

State of Missouri



Needs Assessment & Resource Inventory for Mental Health



Creating Communities of Hope

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EXECUTIVE SUMMARY

Introduction

Of the approximately 5.8 million people who live in Missouri, it is estimated that 10.5%, or approximately 609,000 individuals, suffer from either serious psychological or emotional distress. Furthermore, 11% are alcohol dependent, 3% are drug dependent, and around 1.5% have mental retardation or a developmental disability.¹ The prevalence of these mental health issues is high and demands significant resources to fully meet the needs of all those with mental health issues.

In October 2006, in response to the 2003 President's New Freedom Commission report, the federal government awarded the Missouri Governor's Office a Mental Health Transformation State Incentive Grant (MHT-SIG) to transform mental health care statewide and better meet the needs of persons with mental illness. As a first step toward implementation, a needs assessment and resource inventory (NARI) was conducted by the Missouri Institute of Mental Health (MIMH); the NARI was also designed to assist in the development of the Missouri Comprehensive Mental Health Plan. This report reflects information gathered during Year One. Future updates will expand the scope of the NARI to the needs and resources of regional, local and private providers of mental health care services.

Procedure

MIMH researchers collected information from over 500 individuals through a variety of means including (1) 15 focus groups with 191 consumers²; (2) in-person and telephone interviews with 23 local mental health agency staff; (3) on-line surveys of 184 mental health, substance abuse and mental retardation/developmental disabilities agencies; (4) 14 on-line surveys of Transformation Working Group (TWG) members; and (5) on-line surveys of 108 Transformation Work Group members. Additionally, dozens of secondary sources were consulted, including the "Voice of the Consumer" report (Change Innovation Agency, 2003) which documents the needs of Missouri consumers in in-patient facilities as well as specialized populations, such as the deaf and hearing impaired. The Lieutenant Governor's Report on Safety (Missouri Mental Health Task Force, 2006) was also a valuable resource. Other resources included information from 421 individuals who participated in 14 public hearings designed and conducted by the Transformation Planning Team, as well as findings from focus groups and written surveys conducted for the Missouri Planning Council for Developmental Disabilities Statewide Needs Assessment.

¹ Serious Psychological Distress data is for adults (18+) and Serious Emotional Distress data is for children. Data from the National Survey on Drug Use and Health, Prevalence rate estimates were applied to the Missouri population estimates from the 2005 U.S. Census to get the estimated number of Missourians with serious mental illness.

² Participants included rural, African-American, Hispanic, homeless, and elderly individuals, probationers and parolees, foster care transitional youth, families with children, and immigrants/refugees.

MIMH researchers identified over twenty themes that emerged from the review of existing literature and analysis of primary data sources. These themes are clustered into six domains: (1) Safety; (2) Access to Care; (3) Mental Health Wellness; (4) Consumer-driven Care and Support; (5) Quality Mental Health Care; and (6) Mental Health System Fragmentation. The following table presents these themes with the data sources that provided support for these themes. Large checkmarks indicate that the need was very strong; smaller checkmarks indicate that the need was mentioned frequently but was not felt to be one of the most pressing needs.

Cross-cutting Mental Health Themes by Stakeholder Group³

Strategic Themes	Secondary Sources	Focus Groups and Interviews ⁴	Mental Health/Substance Abuse Agencies ⁵	MR/DD Agencies ⁶	Transformation Working Group ⁷	Transformation Work Groups	“Voice of the Consumer”	Public Hearings
Safety								
Institutional abuse and neglect	√	√					√	√
Trauma-informed care	√	√				√	√	
Preventable medical errors	√	√					√	
Occupational safety	√							
Access to Care								
More providers and beds	√	√	√	√	√	√	√	√
Affordable services	√	√	√	√	√	√		√
Transportation	√	√	√	√	√	√	√	√
Housing and Employment	√	√	√	√	√	√	√	√
Age-specific disparities	√	√	√		√	√		√
Cultural disparities	√	√			√	√	√	√
Mental Health Wellness								
Prevention/early intervention	√	√	√		√	√		√
Stigma/discrimination	√	√	√		√	√		√
Public mental health literacy	√	√	√		√	√	√	√
Mental/Physical Health Integration	√	√			√	√		√
Consumer-driven Care and Support								
Consumer-directed care	√	√	√	√	√	√	√	√
Consumer recovery/support services	√	√	√		√	√	√	√

³ Bold checkmarks indicate that the theme was ranked as one of the most important needs of the relevant stakeholders; smaller checkmarks indicate that the theme was mentioned frequently but did not emerge as one of the highest needs.

⁴ Primary needs of the focus group participants derived from systematic review of all focus group transcripts.

⁵ Structured, closed-ended survey.

⁶ Structured, closed-ended survey.

⁷ Primary needs of the TWG were derived from a needs assessment survey conducted by MIMH.

Strategic Themes	Secondary Sources	Focus Groups and Interviews ⁸	Mental Health/Substance Abuse Agencies ⁹	MR/DD Agencies ¹⁰	Transformation Working Group ¹¹	Transformation Work Groups	“Voice of the Consumer”	Public Hearings
Quality Mental Health Care								
Workforce development , especially for co-occurring disorders	√	√	√	√	√	√	√	√
Use of evidence-based practices	√	√			√	√	√	√
Quality management	√	√			√	√		
Collaboration and coordination (state agencies, state/local)	√		√	√	√	√	√	√
Mental Health System Fragmentation								
Improved financing	√		√	√	√	√		√

⁸ Primary needs of the focus group participants derived from systematic review of all focus group transcripts.

⁹ Structured, closed-ended survey.

¹⁰ Structured, closed-ended survey.

¹¹ Primary needs of the TWG were derived from a needs assessment survey conducted by MIMH.

Cross-cutting Themes

Safety

From key secondary sources supported by focus group and public hearing participants, four primary issues emerged related to safety: (1) abuse and neglect; (2) trauma-informed care; (3) preventable medical errors; and (4) occupational safety. In large part, these concerns are currently being addressed by state agencies. The Lieutenant Governor's Report on Abuse and Neglect (2006) outlines 25 action steps for improving consumer safety, including (1) recruiting and retaining staff by offering more competitive pay; (2) staff training; (3) centralized data collection and analysis capabilities; (4) leadership stability; and (5) abuse and neglect reporting. That report also recommended that the Missouri Department of Mental Health (DMH) pursue implementation of the Mental Health Commission (MHC) recommendations made in their 8/06 report titled "Building a Safer Mental Health System." These priorities come from the feedback of 217 individuals attending public hearings held in 2006 to address issues related to abuse and neglect in state facilities. Additional needs suggested by stakeholders included further efforts to expand trauma-informed care and widespread implementation of alternatives to restraint and seclusion and other methods of improving staff and client safety.

Access to Services and Supports

The NARI explored barriers to receiving both treatment and recovery supports. Easier, faster access to services, affordable services, transportation, additional providers, housing and employment emerged as the most significant barriers to receiving care.

➤ *Easier, Faster Access to Services*

Most stakeholder groups agreed that easier, faster access to services is a major need in the current system. The Transformation Working Group ranked easier access as a high need, and both MIMH and "Consumer Voice" focus groups mentioned difficulty receiving services due to endless waiting lists, bureaucracy, and inadequate crisis services. A need for easier access and a need for "no wrong door" also came out of the focus groups.

➤ *Affordable Services*

Across the board, affordability of services was a predominant theme among Missouri stakeholder groups. Mental health and substance abuse agencies ranked "services to the uninsured" as the number two priority. Ten of the 13 public hearings conducted by the DMH for the Transformation Initiative identified affordability as a major issue, pointing to MO HealthNet (Medicaid) restrictions as a significant impediment to obtaining care. Eight of the 10 focus groups had similar concerns. These groups included the elderly, African-Americans, rural residents, homeless persons, transitional youth, refugees and immigrants, and probation and parolees. Transitional youth often age out of eligibility for children's services with no financial means or steady employment to provide them with health insurance; and parolees and probationers transitioning to society find many barriers to reinstating insurance upon reentry.

➤ *Transportation*

Transportation was consistently identified as a top need according to providers and consumers who were consulted. It was a high or critical need among almost **90%** of mental health care and substance abuse agencies. Among Division of Mental Retardation/Developmental Disabilities (MR/DD) providers, transportation emerged as the fourth most needed service. Transportation was a major problem for individuals in five of the ten focus groups, and six out of thirteen public hearing sites, particularly those held in rural areas. Elderly individuals who cannot drive are in need of mobile services and youth in rural areas reported needing transportation to drive to the closest service providers, which are often in metropolitan areas. Transportation is also a major issue for the homeless, who have difficulty getting services and gaining employment without reliable transportation. Hispanics also reported that lack of transportation makes it less likely that they will seek services. Telehealth and, in-home services were suggested way to provide services in rural areas while alleviating the demand for transport; provision of services in communities would be ideal.

➤ *Additional Providers*

More providers, especially those trained to provide specialized services, was repeatedly cited as a strong need. More specifically, geriatric and child psychiatrists, and providers specialized in treating co-occurring disorders are in very high need. Participants at public hearings also reported that psychiatrists are a very strong need; seven of thirteen sites mentioned a need for more psychiatrists or prescribing doctors. Other provider needs included interpreters and professionals trained to work with deaf, international, African-American and Hispanic consumers, according to focus groups conducted by both MIMH and “Consumer Voice,” and people at public hearings. Several MIMH focus groups and participants at public hearings felt that “natural” community caretakers, including members of the faith community and nursing home personnel could be trained in mental health care to provide more information to the community, reduce stigma and encourage accessing mental health services. More in-patient and residential care (especially for co-occurring disorders) was also an expressed need of several stakeholder groups, including mental health and substance abuse agencies, public hearings, and focus groups conducted by MIMH and “Consumer Voice”.

Mental Health Wellness

➤ *Prevention/Early Intervention*

Prevention and early intervention are major needs according to the MIMH focus groups, the “Consumer Voice” report, the public hearings, and mental health and substance abuse agencies. Specifically, prevention for at-risk youth was particularly important to the focus groups, while mental health and substance abuse agencies emphasized school-based mental health services. A number of recommendations resulted from the work groups, including coordinating existing prevention plans, training providers on prevention strategies, and linking mental health professionals with local public health offices. Eight of thirteen public hearing sites felt prevention was a high priority, and participants from several sites suggested linking mental health with schools and increasing suicide prevention efforts.

➤ *Stigma and Discrimination*

Reducing stigma and discrimination was a very high priority need for the TWG, focus group members and public hearing participants. Stigma reduction was mentioned by *all* MIMH focus

groups. The TWG ranked “improving the public perceptions of persons with mental health needs” as the third most important need in the state. Focus group members from the “Consumer Voice” report believed that stigma from the community and mental health staff is an impediment to recovery. Public hearings indicated support for an anti-stigma campaign.

➤ *Public Mental Health Literacy*

Focus group consumers and public hearing participants felt strongly that the public needed more and better information about mental health wellness and how to obtain treatment. Members from several focus groups said that they were unaware of any mental health literature in their community and believed that additional information would both help de-stigmatize mental illness and increase the number of persons seeking treatment. Transitional youth, families with children and public hearing participants felt that mental health curricula should be placed in high schools, possibly as part of regular health classes. Hispanic and immigrant/refugee focus group members felt that all mental health information should be translated into the appropriate language, so that minorities can be educated about mental illness.

➤ *Integration of Physical/Mental Health*

The integration of mental and physical health was a need expressed by three of the groups; the MIMH focus groups, five out of thirteen public hearing sites, and mental health and substance abuse agencies providers. Among the focus groups, integration placed 8th in their needs; providers ranked it as 10th. This need was particularly strong for the elderly, where a very high proportion of seniors with mental health needs also have chronic physical illnesses that link them to the health care system. The same is also true for rural Missourians, who often have little access to mental health specialists and therefore often visit family physicians for mental health issues. In addition, families with children pointed out that children with mental illness often have physical illnesses as well, and that both should be considered in an integrated system of care.

Consumer-driven Care and Recovery Services

➤ *Consumer-driven Care*

Consumer-driven care was a high priority need expressed by *all* groups, whether they were consumers, agency staff, workgroup members, or public hearing participants. TWG members felt that consumer-driven care was a critical need and should be one of the first priorities taken in the transformation effort. Several MIMH and “Consumer Voice” focus group members, as well as public hearing participants, felt that they were not being heard in the current system and that they should be better involved in the treatment decision-making process. Consumer-driven care was the third most important need for which MR/DD agencies would advocate if allowed to choose only one issue.

➤ *Consumer-driven Recovery Services*

Improved consumer recovery and support services were a strong need among mental health and substance abuse providers, MIMH and “Consumer Voice” focus group members, and public hearing participants. In particular, more consumer-driven support services (peer supports, consumer-operated service providers, etc.) are desired, particularly by public hearing participants (peer supports were mentioned at six of thirteen sites). Provider agencies listed this as their second most important need. Focus group consumers, including transitional youth and rural consumers

expressed frustration with the quality and accessibility of existing support services. Persons on probation or parole expressed concern that, after their release from correctional facilities, many support services are no longer available to them, including medication for mental health disorders identified prior to their incarceration or while in the correctional facility. Transformation Work Group members made several recommendations, including the expansion of evidence-based peer and family-run programs to help strengthen existing recovery and support services.

Quality Mental Health Care

➤ *Workforce Development and Training*

Workforce development, particularly in the area of co-occurring disorders, was a strong need among providers, focus groups, Transformation Work Groups, and public hearing participants. A total of 82% of mental health and substance abuse providers indicated that training in co-occurring disorders is a high or critical need. Co-occurring disorders training and treatment ranked as the #1 need for which these agencies would advocate if they could choose only one issue. Co-occurring disorder training was the fourth greatest need for MR/DD providers. The need for more co-occurring services is also a theme among focus group consumers. In addition, several MIMH and “Consumer Voice” focus groups felt that their counselors did not have adequate skills to provide quality counseling services.

➤ *Use of Evidence-based Practices (EBP)*

Needs related to evidence-based practices stemmed primarily from the Evidence-based Practice Transformation Work Group, focus group participants, and providers. Almost three-fourths of providers felt that training in evidence-based practices was either a high or critical need. The Work Group saw the need to develop: (1) policies, regulations and financing strategies that support Evidence Based Practices (EBP); (2) a policy statement that ensures broad-based input into EBP funding; (3) provider financing incentives to support EBP development and practice; (5) consumer choice of providers certified in an EBP by DMH; (6) “Coordinating Centers of Excellence” to identify and promote the use of EBPs; (7) a training curriculum for EBP core competency development; (8) education and licensure incentives for continuing education in evidence-based practices; and (9) partnerships with colleges and universities to incorporate EBP into course curricula and provide training opportunities in practice and implementation. Assessment of program fidelity and on-going monitoring of new EBPs was also recommended as a priority. The need for EBPs was reflected in consumers’ stated needs for better quality services, particularly in the area of counseling.

➤ *Quality Management and Use of Technology*

While the mental health system of care has considerable procedures and technological resources to assure quality management, the Transformation Work Groups identified several steps necessary to further improve the current system. They include: (1) the development of a unique consumer identifier, for use across departments, to improve treatment coordination for individual consumers; (2) Advanced Information Technology systems that fully integrate quality management databases; (3) systematic and comprehensive evaluation of department quality management procedures and programming; (4) an Electronic Health Record (EHR) system that is owned by the consumer and shared with providers ; (5) Electronic Medical Records system (EMR); (6) systematic data analysis. (7) outcome analysis; (8) e-based information sharing system; (9) e-based system for training; and (10) expanded teleconferencing to improve program monitoring and communication.

Mental Health System Fragmentation

Collaboration and co-ordination were predominant themes for the TWG, agency providers, “Consumer Voice” focus groups, and public hearing participants. DMH provider agencies surveyed felt strongly that further collaboration between DMH divisions, across departments in state government, and with public/private agencies is critical--about 75% of providers reported either a high or critical need for collaboration in these three areas. Individual consumers and public hearing members voiced concerns about fragmentation as well, expressing the need for better coordination between schools and mental health care providers, substance abuse and mental health care services, and primary care and mental health care professionals. Comments from the public hearings also emphasized the need for an interdepartmental leadership structure, consistent service areas, integrated funding, and a shared service philosophy. MIMH focus groups reported the need to have mental health services better incorporated into their communities, as opposed to a more centralized system. All groups mentioned the need to improve the current financial system, with several stakeholder groups arguing for more effective funding strategies.

Key Needs Identified from NARI Data Sources

The cross-cutting themes described above evolved from an analysis of data collected specifically for the NARI and from secondary sources directly related to mental health needs. While more completely described in the full report, major needs included: (1) access to care (including a single point of entry into the mental health care system); (2) improved financing; (3) agency collaboration/coordination; (4) stigma reduction/public literacy; (5) transportation; (6) housing; (7) recovery/support services; (8) co-occurring disorder training; (9) expanded school-based mental health; (10) more specialized providers and training; (11) affordable services; and (12) prevention/early intervention. The table on the following page lists these priorities in detail.

Stakeholder Priority Needs*

Stakeholder Group	Priority Needs	
Transformation Working Group members	Most Pressing Needs <ol style="list-style-type: none"> 1. Improved financing 2. Increased access to mental health care 3. Agency collaboration Critical Actions Needed <ol style="list-style-type: none"> 1. Improved financing 2. Consumer-driven care 3. Stigma reduction 	First Steps Toward System Transformation <ol style="list-style-type: none"> 1. Improved financing 2. Agency collaboration 3. Consumer-driven care 4. Stigma reduction 5. Increased access to mental health care 6. Workforce development 7. Use of evidence-based practices 8. Political buy-in
Transformation Work Group members (n=108)	Priority Needs <ol style="list-style-type: none"> 1. Increased access to mental health care 2. Improved financing 3. Agency collaboration 4. Public mental health literacy/stigma reduction 5. Consumer supports 6. Prevention/Public Health Model/Across Lifespan 7. Technology 8. Early identification 	
Focus group members/interviewees	Priority Needs <ol style="list-style-type: none"> 1. Stigma reduction 2. Community involvement/outreach 2. Affordable Services 4. Specialized Providers (esp. psychiatrists) 5. Transportation 5. Increased access to mental health care 5. Prevention/Early Intervention 	<ol style="list-style-type: none"> 8. Mental/physical health integration 8. Consumer-driven care 8. Public mental health literacy 8. Ongoing recovery/support services
Mental health and substance abuse providers	Most Pressing Needs <ol style="list-style-type: none"> 1. Co-occurring disorders training/treatment 2. Affordable services 3. Better co-ordination of services 4. Community support services 5. Greater consumer choice 6. Improved financing 	Consumer Needs <ol style="list-style-type: none"> 1. Single point of entry into system 2. Transportation assistance 3. Ongoing recovery/support services 4. Provider co-occurring disorder training 5. Expanded school-based mental health services 6. Better evaluation of persons with co-occurring disorders
MR/DD providers	Needs for System Change <ol style="list-style-type: none"> 1. Improved financing 2. Better coordination/consistency of services 3. Consumer-driven care 4. Better pay for providers and staff 5. Ongoing recovery/support services 6. Psychiatric services 	Consumer Needs <ol style="list-style-type: none"> 1. Shorter waiting lists for housing 2. Affordable housing 3. Behavior management services 4. Transportation 5. Employment 6. Better paying jobs

Stakeholder Group	Priority Needs
Public Hearing Participants	1. Ongoing recovery/support services 1. Agency collaboration 1. Workforce development 4. Housing 4. Revised Medicaid coverage/eligibility requirements 4. Specialized providers (esp. psychiatrists) 7. Transportation 8. Improved financing 8. Expand school-based mental health services 8. Co-occurring disorder services

*Duplicate numbers reflect ties.

State Resources

For the NARI, the MIMH team gathered information on the amount spent on mental health care across state departments, the number of persons served by the DMH, state-level mental health services, consumer-operated mental health organizations, and available technological resources. In FY 2006, it was estimated that over two billion dollars was spent on mental health service expenditures in Missouri. Around 55% of those expenditures were for DMH services and around 39% were MO HealthNet (Medicaid) dollars (non-DMH), with the remaining expenditures spread across the Departments of Elementary and Secondary Education, Health and Senior Services, Corrections, and Social Services. As some expenditures were still being calculated at the time of this writing, total expenditures are predicted to be slightly higher.

In FY 2006, DMH served 144,644 consumers. Forty-three percent received psychiatric services, 30% received substance abuse services, 18% received mental retardation and developmental disability services and 9% received services for co-occurring disorders. These numbers represent consumers with services paid for through the DMH; the Division of Alcohol and Drug Abuse Substance Abuse (ADA) traffic program services another 19,095 consumers that self-pay for services.

Structure of the Report

This chapter has summarized the major themes that emerged from the needs assessment and resource inventory. The full report contains an expanded discussion of each of the key findings/cross-cutting themes, comprehensive information regarding each of the data sources, and a preliminary inventory of mental health resources at the state level to be enhanced this coming year. Chapters are as follows:

- Introduction:* *A Snapshot of Missouri.* Describes the general demographic characteristics of Missourians.
- Chapter One:* *Mental Health in Missouri across the Life Span: Estimates of Prevalence, Financial Resources and Consumer Profiles.* Estimates prevalence rates for mental illness, substance abuse and mental retardation/developmental disabilities. Provides financial resources designed to meet those needs and descriptions of mental health consumers.
- Chapter Two:* *NARI Key Themes.* Documents the major themes that emerged from the analysis of data sources described in subsequent chapters.

- Chapter Three: Needs According to Transformation Work Groups.* Presents results from on-line surveys of Transformation Work Group members.
- Chapter Four: Summary of Needs from Department of Mental Health-related Sources.* Summarizes the findings from pre-existing Department of Mental Health-related sources, including focus groups comprised of consumers in in-patient care, special populations, providers and advocacy groups.
- Chapter Five: Needs According to Mental Health Consumer Interviews and Focus Groups.* Presents key findings and background information from all focus groups and interviews conducted for the NARI.
- Chapter Six: Substance Abuse and Mental Health Provider Agency Survey: Needs and Resources.* Describes the characteristics, needs and resources available to substance abuse and mental health providers obtained from on-line surveys provider surveys.
- Chapter Seven: MR/DD Provider Agency Survey: Needs and Resources.* Describes the characteristics, needs and resources available to providers of mental retardation and developmental disabilities services obtained from on-line provider surveys.
- Chapter Eight: Missouri Mental Health Services and Resources.* Presents mental health, substance abuse, and MR/DD programs and services provided by all state agencies. Describes consumer-driven recovery and support services and technological mental health resources available to state agencies.

INTRODUCTION: A SNAPSHOT OF MISSOURI

Geographically, Missouri is the 21st largest state in the United States with 69,704 square miles. It ranks 17th in population, with approximately 5.8 million people. It is often referred to as “The Gateway to the West.” The state of Missouri was named for the local Sioux Indian tribe, whose name translates to “the wooden canoe people.”

Population

- 73% of Missouri residents live in metropolitan areas, half of which are in the two largest metropolitan areas: St. Louis on the eastern border and Kansas City on the western border.
- The age distribution is roughly equivalent to the national average, with 6.5% of the Missouri population under 5 years old, 24.1% under 18 years old, and 13.3% 65 and over. Two percent are 85 years of age or older. The percentage of persons 85 and older increased by 21.4% during the 1990s.
- Missouri has many fewer (2.7%) foreign-born residents compared with the national average (11.1%). Missouri also has fewer bilingual households (5.1%) than the national average (17.9%).

Ethnicity

- The majority (85.4%) of Missouri’s population is White. 11.5% of Missourians identify themselves as Black/African-American, 2.6% Hispanic/Latino, 1.3% Asian, and 0.5% Native American.
- Although still small in size, the Hispanic population more than doubled in 56 Missouri counties from 1990 to 2000.
- African-Americans constitute 15.8% of the urban population in Missouri, but only 1% of the rural population.

Income

- The estimated median household income in 2006 was \$42,841, ranking it 37th among all states.
- 13% of Missourians were living below the poverty level in 2005.
- 19% of Missouri children under age 18 were living in poverty in 2005, and 8% were living in extreme poverty, defined as at or below 50 percent of the federal poverty level.
- The largest concentration of poverty is in the rural areas of the state, particularly southeastern Missouri. Of the 16 Missouri counties identified as “persistent poverty counties” by the Economic Research Service (ERS), 14 were located in Southeastern Missouri. ERS defines a persistent poverty county as a county where 20% or more of residents were poor as measured by the last four censuses (1970, 1980, 1990, and 2000).

(Estimates from U.S. Census Bureau, 2007).

CHAPTER ONE

MENTAL HEALTH ACROSS THE LIFE SPAN: PREVALENCE ESTIMATES, FINANCIAL RESOURCES AND CONSUMER PROFILES

Background

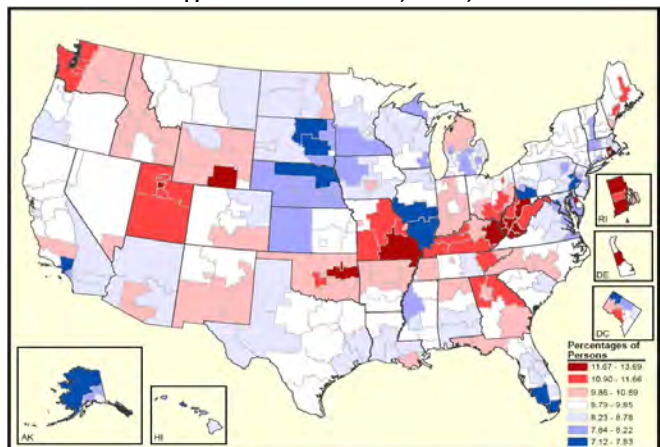
This chapter presents the best available data on the prevalence of mental health difficulties among Missourians across the lifespan. Also presented are data on the number of consumers served by the Missouri Department of Mental Health (DMH) and MO HealthNet (Medicaid), and related expenditures, as well as preliminary data from other state departments involved in the delivery of mental health care in Missouri. Finally, estimates of the needs met through the state departments are explored.

Prevalence across the Life Span

The prevalence data in this chapter focuses primarily on the prevalence of mental illness, substance dependence and abuse, and mental retardation and developmental disabilities (MR/DD) in the Missouri population. Also included are co-occurring substance use and mental disorders. Future reports will further explore co-occurring disorders, provide updated estimates for mental illness among poor Missourians, as well as improved estimates of unmet need and the prevalence of mental illness among vulnerable individuals in state-run institutional facilities, such as in corrections, mental health facilities, nursing and senior facilities, and the child welfare system. In addition, data regarding mental health expenditures within state departments other than DMH and MO HealthNet will be provided.

Of the approximately 5.8 million people who live in Missouri, an estimated 10.5%, or over 609,000 individuals, suffer from either serious psychological or emotional distress. Further, around 11% are alcohol dependent, 3% are drug dependent, and around 1.5% have been diagnosed with mental retardation or a developmental disability. The highest rates of mental illness and substance abuse are among transitional youth ages

Serious Psychological Distress among Persons Aged 18 or Older, by Substate Region: Percentages, Annual Averages Based on 2002, 2003, and 2004



Source: National Survey on Drug Use and Health, 2002, 2003, and 2004.

18-25. They also have the highest rates of co-occurring disorders, with almost half of transitional youth with mental illness also experiencing substance abuse issues. For individuals aged 18 and older, the highest rate of serious psychological distress is in the southeast portion of the state. The table below includes prevalence rates across the lifespan for Missourians with mental illness, alcohol and drug dependence and abuse, and mental retardation/development disabilities issues. Total prevalence for Missouri is based on the total estimated 2005 population of 5.8 million (5,800,310) (U.S. Census, 2005). Specific definitions and data sources for the population and prevalence estimates provided in the table are also listed below.

Estimated Percent (Number) of Missouri Population with Mental Health Difficulties in Past Year, by Age Group, 2005

	Mental Illness	Alcohol Dependence or Abuse	Drug Dependence or Abuse	Mental Retardation/ Developmental Disabilities
Children &/or Adolescents (4-17)	8.7%	7.0% ¹²	5.7% ¹²	3.4%
Transitional Youth (18-25)	15.5%	21.0%	9.6%	.79%
Adults (26-64)	12.8%	7.0%	1.5%	.9%
Elderly (65 and older)	4.6%	1.6%	0.1%	.4%
TOTALS	10.5% (609,032)	10.9% (486,494)	2.6% (178,864)	1.49% (86,424)

Definitions

Definitions of what constitute mental illness, mental retardation/developmental disabilities, and substance use and dependence can vary widely across professional organizations, government entities, mental health providers, and even consumers themselves. Terms used in this document are defined as follows:

Mental Illness. Mental illness is defined differently for children and adults. In this report, an adult is considered to have “mental illness” if he/she has experienced Serious Psychological Distress (SPD) in the past year. For children, mental illness is defined as the experience of moderate or severe Serious Emotional Disturbance (SED) in the past year. See below for the definitions of both terms.

Serious Psychological Distress (SPD). Estimates of serious psychological distress come from the National Survey on Drug Use and Health (NSDUH). The NSDUH is a national telephone survey conducted annually by the Substance Abuse and Mental Health Services Administration (SAMHSA). To measure (SPD), the NSDUH utilizes the K6 scale, a screening instrument for non-specific psychological distress. The scale was originally designed to measure Serious Mental Illness (SMI)

¹² Number is based on estimates for the 12-17 age range. Substance abuse and dependence estimates for children younger than 12 were not available.

until a few years ago, in which the name was changed to Serious Psychological Distress. The NSDUH measures psychological distress for all participants aged 18 and older.

Serious Emotional Disturbance (SED). In the state of Missouri, youth under the age of 18 who exhibit “substantial impairment in their ability to function at a developmentally appropriate level due to the presence of a serious psychiatric disorder” are deemed to have a (SED). For the NARI, the prevalence estimate of SED from the National Survey of Children’s Health (NSCH, 2003) was used, which included moderate and severe SED.

Mental Retardation/Developmental Disabilities. Prevalence estimates of mental retardation/developmental disabilities come from the 1994 and 1995 National Health Interview Survey's Disability Supplement (NHIS-D). The American Association on Mental Retardation (AAMR) defines **mental retardation** as the co-occurrence of “significantly sub average intellectual functioning . . . with related limitations in two or more adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work,” with such limitations manifested “before age 18” (Luckasson, et al., 1992, p. 1). **Developmental disability** is defined by the Developmental Disabilities Act as a “severe, chronic disability” attributable to “mental” and/or “physical” impairments that are “likely to continue indefinitely”; resulting in substantial functional limitations in three or more “major life activity areas”: self-care, receptive or expressive language, learning, self-direction, capacity for independent living and economic self-sufficiency; manifested by age 22 and requiring care, treatment or other services of lifelong or extended duration” (The Developmental Disabilities Assistance and Bill of Rights Act, 2000).

Alcohol/Drug Dependence or Abuse. Estimates of alcohol dependence and abuse, as well as estimates of drug dependence and abuse, came from the 2004 and 2005 NSDUH (Wright, Sathe, and Spagnola, 2007). To diagnose alcohol and drug dependence and abuse, the NSDUH uses criteria in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV).

Detailed Prevalence Estimates

While a previous table supplies the general prevalence estimates by age group, the following sections examine the methodology for estimating Missouri prevalence rates in more detail. The sections are divided by age group, and discussed in the following order:

- Children (ages 4-17)
- Transitional Youth (ages 18-25)
- Adults (ages 26-64)
- Elderly (ages 65 and older)

In addition, preliminary estimates of treatment needs met by DMH and prevalence among the poor, is discussed briefly at the end of the chapter. Phase II of the NARI will develop these topics in greater detail.

Children & Adolescents (Ages 4-17)

Mental Illness

Estimates of the percentage of U.S. children suffering from SED range from 5% to 9%. According to the National Survey of Children's Health (NSCH, 2003), 8.7% of children and youth (ages 4 – 17) in Missouri have moderate or severe difficulties in the areas of emotions, concentration, behavior, or the ability to get along with others, compared to 9.2% of the national population of children of the same age. The National Health Interview Survey (NHIS, 2005), reported that 5.4% of children ages 4 to 17 had severe difficulties in 2004. The variation in the statistics reported by NHIS (2005) and by NSCH (2003) is due to the inclusion of both moderate and severe emotional disturbance by the NSCH, while the NHIS only includes severe emotional disturbances. The table below shows the estimated number of Missouri children with moderate and/or severe emotional and behavioral difficulties.

Estimated Percent (Number) of Missouri Children (Aged 4-17) with Serious Emotional Disturbance, 2005

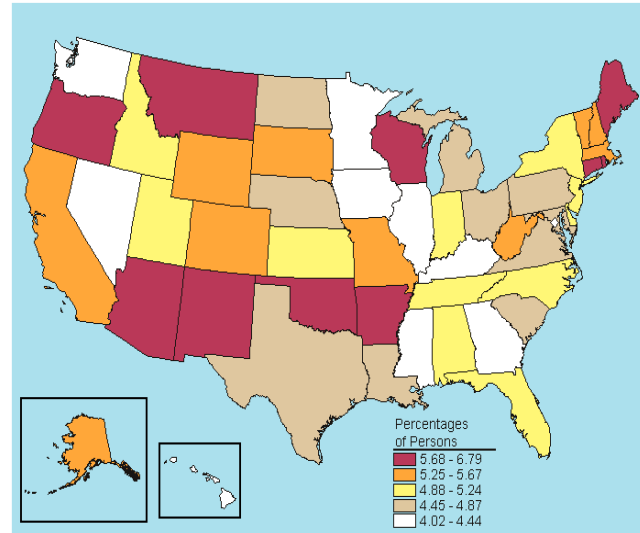
	Estimated Missouri Child Population 2005	Prevalence of "Moderate or Severe" SED	Prevalence of "Severe" SED
Percent (Number)	1,076,206	8.7% (93,629)	5.4% (54,115)

Source: Prevalence of "Moderate or Severe" SED based on an 8.7% one year prevalence rate estimated by the National Survey of Children's Health (NSCH, 2003). Prevalence of Severe SED is based on 5.4% one year prevalence estimate by the National Health Interview Survey (NHIS, 2005).

Illicit Drug Use and Abuse

The 2004 and 2005 National Survey on Drug Use and Health (NSDUH) provide data on illicit drug use for children and adolescents aged 12-17 (Wright, Sathe, and Spagnola, 2007). The results indicate that, overall, Missouri adolescents use illicit drugs at a rate higher than national averages. The rate of marijuana use among Missouri youth aged 12-17 in the last year (15.0%) is higher than the national average of 13.9%. The Missouri rate of use of illicit drugs other than marijuana (5.7%), non-medical use of painkillers (7.7%), and cocaine use (1.7%), were also slightly higher than the national averages (Wright, Sathe, and Spagnola, 2007). The rate of illicit drug abuse or dependence for Missouri youth aged 12-17 was 5.67%, once again slightly above the national average of 5.0% (see figure at right).

State Percentages of Illicit Drug Abuse or Dependence in Past Year among Persons Aged 12-17



Source: National Survey on Drug Use and Health, 2004 and 2005.
Map Prepared by: SAMHSA, Office of Applied Studies

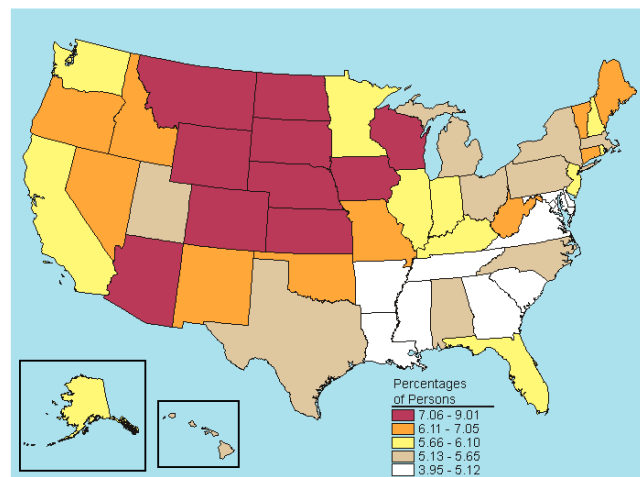
Alcohol Use and Abuse

According to the 2004 and 2005 NSDUH, the rate of alcohol dependence or abuse in the past year among youth was 7%, compared to 5.8% for that age group nationally (see figure at right).

Co-occurring Mental Illness/Substance Use Disorders

Data on the percentage of Missouri children or adolescents experiencing co-occurring alcohol or substance dependence and SPD are not available. However, existing national data indicate that the rates of SPD and substance abuse among adolescents aged 12-17 tend to be lower than those for youth ages 18-25, but higher than rates for adults (Wright, Sathe, and Spagnola, 2007). Since, according to the 2005

State Percentages of Alcohol Abuse or Dependence in Past Year among Persons Aged 12-17



Source: National Survey on Drug Use and Health, 2004 and 2005.
Map Prepared by: SAMHSA, Office of Applied Studies

NSDUH, the rate of co-occurring disorders among youth ages 18-25 is 6.6%, and the rate for adults 26-64 is 1.6%, it is likely that the rate for adolescents aged 12-17 is somewhere in between those two numbers.

Mental Retardation/Developmental Disabilities

State-level prevalence data for mental retardation/developmental disabilities among children and adolescents do not exist. The most recent national prevalence data for mental retardation/developmental disabilities come from the disability supplement of the 1994/1995 National Health Interview Survey (Larson, Lakin, Anderson, Kwak, Lee, & Anderson, 2001). The results of the survey are shown in the table below. Since developmental disabilities are automatically diagnosed for children under the age of 5 with mental retardation, the prevalence of “mental retardation not developmental disabilities” is zero. Approximately 38 per 1,000 children aged 0-5 had mental retardation and/or developmental disabilities, as well as 32 per 1,000 children aged 6-17 (Larson et. al., 2001). Application of these figures to the 2005 U.S. Census Missouri population estimates yields 17,182 Missouri children aged 0-5 with mental retardation and/or developmental disabilities and 29,505 children aged 6-17. That is a total of 46,687 children under the age of 18 with mental retardation/developmental disabilities (a combined rate of 33.9 per 1,000 population).

Estimated Prevalence Rates of MR/DD in the U.S. Population among Children and Adolescents (per 1,000 population)

Prevalence per 1,000 U.S. Non-institutionalized Population				
Age	DD not MR	MR not DD	Both MR and DD	MR and/or DD
0-5	33.9	0	4.5	38.4
6-17	11.4	12.2	8.1	31.7

Source: Larson, Lakin, Anderson, Kwak, Lee, & Anderson (2001).

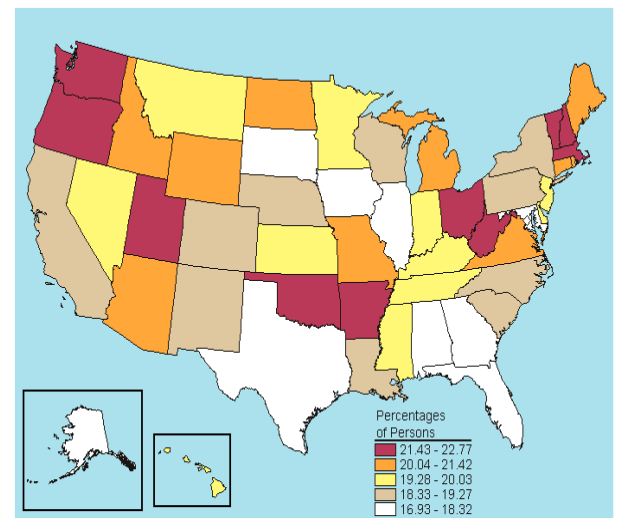
Transitional Youth (Ages 18-25)

Mental Illness

The transition from adolescence to adulthood includes both physical and mental developmental challenges that result in particular vulnerability to mental illness among youth transitioning to adulthood. The term “transitional youth” has been used to refer to youth as young as 16 years of age, but in this study it refers to individuals between the ages of 18-25.

Based on state averages from the 2004 and 2005 NSDUH, it is estimated that approximately 21.3% of Missouri transitional youth aged 18-25 (approximately 91,402 young adults) suffer from SPD in any given year (Wright, Sathe, and Spagnola, 2007). This is compared to approximately 10.0% of adults aged 26-64. The figure at right compares Missouri to the rest of the nation. Missouri’s rate of SPD for transitional youth is higher than the national average.

Percent of Youth Aged 18-25 with Serious Psychological Distress in Past Year



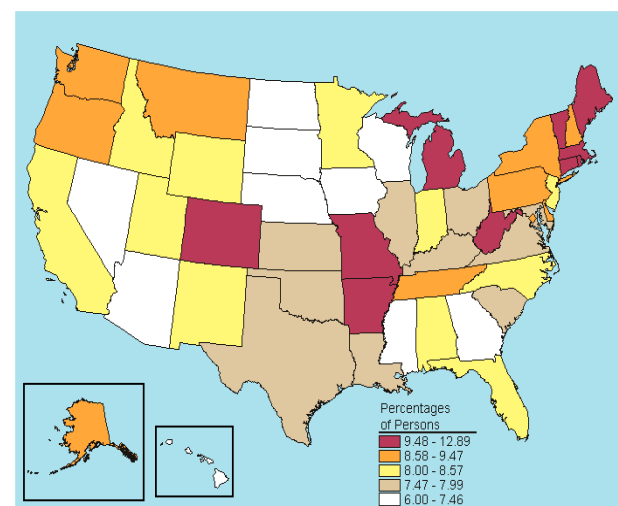
Source: National Survey on Drug Use and Health, 2004 and 2005.

Map Prepared by: SAMHSA, Office of Applied Studies

Illicit Drug Use and Abuse

The rate of marijuana use in the last year (27.0%) for Missourians aged 18-25 is lower than the national average. The Missouri rate of use of illicit drugs other than marijuana (8.6%) was in the average range compared to the nation, as was the Missouri rate of non-medical use of painkillers (12.8%) (Wright, Sathe, and Spagnola, 2007). However, the rate of cocaine use in the past year among Missourians aged 18-25 was high at 8.2%, compared to the national average of 6.8% (SAMHSA Office of Applied Studies, 2007). Overall, according to the 2004 and 2005 NSDUH, the rate of illicit drug dependence or abuse in the past year among Missourians aged 18-25 was 9.6%, compared to a national rate for that age group of 8.4% (see figure at right).

State Percentages of Illicit Drug Abuse or Dependence in Past Year among Persons Aged 18-25



Source: National Survey on Drug Use and Health, 2004 and 2005.

Map Prepared by: SAMHSA, Office of Applied Studies

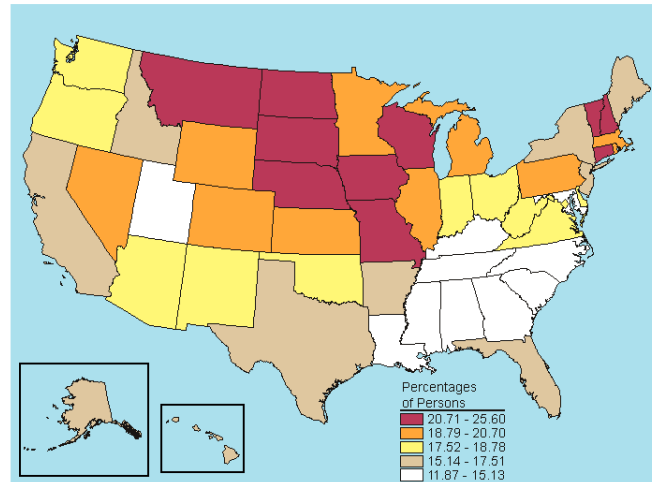
Alcohol Use and Abuse

According to the 2004 and 2005 NSDUH, the rate of alcohol dependence or abuse in the past year among Missourians aged 18-25 was 21% (see figure at right), compared to 18% for that age group nationally, and 7% for Missourians 26 and older (Wright, Sathe, and Spagnola, 2007).

Co-occurring Mental Illness/Substance Use Disorders

State data on the percentage of Missouri youth ages 18-25 experiencing co-occurring alcohol or substance dependence and SPD are not available, but nationally an estimated 6.6% of the national population (aged 18-25) experienced co-occurring SPD and alcohol or drug dependence in 2005 ((Wright, Sathe, and Spagnola, 2007). However, among those transitional youth with mental illness, an estimated 43% also have a co-occurring substance use disorder.

State Percentages of Alcohol Abuse or Dependence in Past Year among Persons Aged 18-25



*Source: National Survey on Drug Use and Health, 2004 and 2005.
Map Prepared by: SAMHSA, Office of Applied Studies*

Mental Retardation/Developmental Disabilities

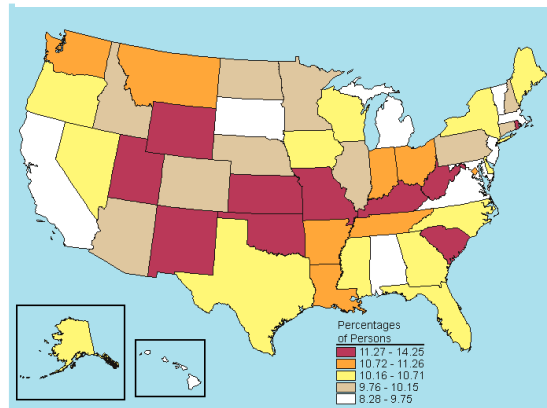
State rates of mental retardation/developmental disabilities specific to the 18-25 age group are not available. However, the disability supplement of the National Health Interview Survey (NHIS) 1994/1995, cites national rates for adults ages 18 and older (Larson et al., 2001). Approximately 0.79% of the population aged 18 and older experienced mental retardation and/or developmental disabilities in the NHIS sample. Application of that percentage to 2005 U.S. Census population estimates for Missouri yields approximately 4,661 youth aged 18-25 with mental retardation/developmental disabilities.

Adults (Ages 26-64)¹³

Mental Illness

Based on average estimates from the 2004 and 2005 NSDUH, approximately 12.8% of Missourians aged 26 and older experience SPD in any given year, compared approximately 10% of adults in the United States¹⁴ (Wright, Sathe, and Spagnola, 2007; See table below). Because the NSDUH does not provide separate estimates for those 26-64, estimates of SPD are derived from the 2005 U.S. Census population count. Based upon these data, approximately 297,455 adult Missourians aged 26-64 experienced SPD in the last year (see elderly section for estimates for adults 65 and older). The rate is even higher among young adults aged 18-25 (see section on transitional youth).

State Percentages of Serious Psychological Distress among Persons Aged 26 and Older



Source: National Survey on Drug Use and Health, 2004 and 2005.

Map Prepared by: SAMHSA, Office of Applied Studies

Prevalence of Serious Psychological Distress (SPD) among Adults in Missouri Aged 26-64.

	Estimated SPD Adult One-year Prevalence Percent	Estimated Adult (26-64) Population 2005	Estimated SPD Adult Prevalence One-year Count 2005
United States	10%	156,852,548	15,685,254
Missouri	12.8%	2,974,552	380,742

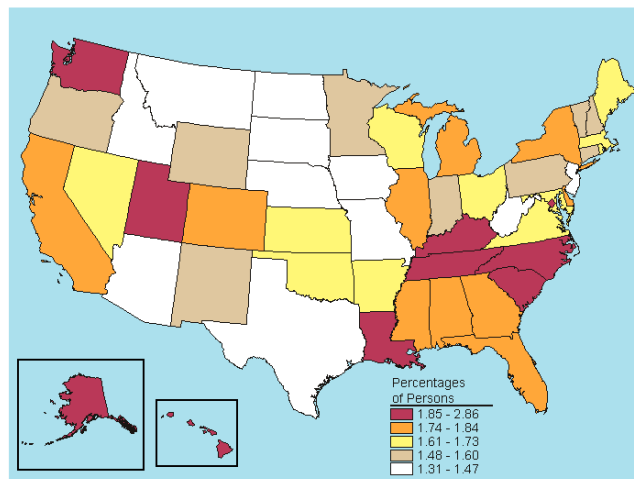
Source: Percents based on aggregate adult (age 26 and older) prevalence rates from the 2004 & 2005 National Survey on Drug Use and Health (NSDUH).

¹⁴ Estimates of SPD, and alcohol and drug use and abuse specific to the 26-64 age range were not available, so estimates for individuals aged 26 and older were used. Since older adults tend to have lower rates of psychological distress and substance abuse than younger adults, the rates of SPD and substance abuse for the 26 and older population may be an underestimate of SPD and substance abuse for the population aged 26-64.

Illicit Drug Use and Abuse

Data from the 2004 and 2005 NSDUH suggests adults 26 and older are much less likely to use illicit drugs than their younger counterparts (Wright, Sathe, and Spagnola, 2007). Furthermore, Missouri adults 26 and older of age are less likely to use illicit drugs than adults of other states. For example, in Missouri, the rates of marijuana use in the last year (7.1%) and cocaine use in the past year (1.5%) were much lower than the national averages. The Missouri rate of use of illicit drugs other than marijuana (2.5%) was in the average range compared to the nation, as was the rate of non-medical use of painkillers (3.2%). Finally, according to the 2004 and 2005 NSDUH, the rate of drug dependence or abuse in the past year among Missourians for adults was lower than national rates (see figure at right).

State Percentages of Illicit Drug Dependence or Abuse in Past Year among Persons Aged 26 and Older

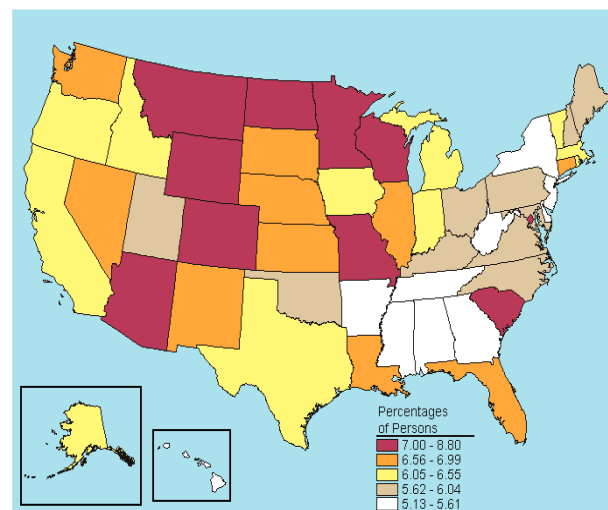


Source: National Survey on Drug Use and Health, 2004 and 2005.
Map Prepared by: SAMHSA, Office of Applied Studies

Alcohol Dependence and Abuse

Although the rate of alcohol use is generally lower in Missouri compared to the rest of the nation for the 26 and older age group, the rate of alcohol dependence or abuse is higher (maps for 26-64 year olds not available) (Wright, Sathe, and Spagnola, 2007). Alcohol abuse and dependence among Missourians in the 26 and older age range was 7%, compared to 6.3% for the same age group nationally (Wright, Sathe, and Spagnola, 2007). The figure at right contrasts rates of use for adults (26 and older) in Missouri compared to the rest of the nation (maps for 26-64 year olds are not available). Alcohol dependence and abuse was higher in Missouri than most other states.

State Percentages of Alcohol Dependence or Abuse in Past Year among Persons Aged 26 and Older



Source: National Survey on Drug Use and Health, 2004 and 2005.
Map Prepared by: SAMHSA, Office of Applied Studies

Co-occurring Mental Illness/Substance Use Disorders

State data on the percentage of Missouri adults experiencing co-occurring alcohol or substance dependence and SPD are not available, but nationally, an estimated 1.6% of adults (26 and older) experienced co-occurring SPD and alcohol or drug dependence in 2005 (data for 26-64 year olds not available) (Wright, Sathe, and Spagnola, 2007). This is compared to a national average of 2.3% for all age groups.

Mental Retardation/Developmental Disabilities

State rates of mental retardation/developmental disabilities specific to the 26-64 age group are not available. However, national rates are available based on the disability supplement of the National Health Interview Survey (NHIS) 1994/1995. Approximately 0.9% of the adult population (aged 26-64) experienced mental retardation and/or developmental disabilities in the NHIS sample. Application of that percentage to 2005 U.S. Census population estimates for Missouri yields approximately 26,771 Missourians aged 26-64 with mental retardation/developmental disabilities.

Elderly (Ages 65 and Older)

Mental Illness

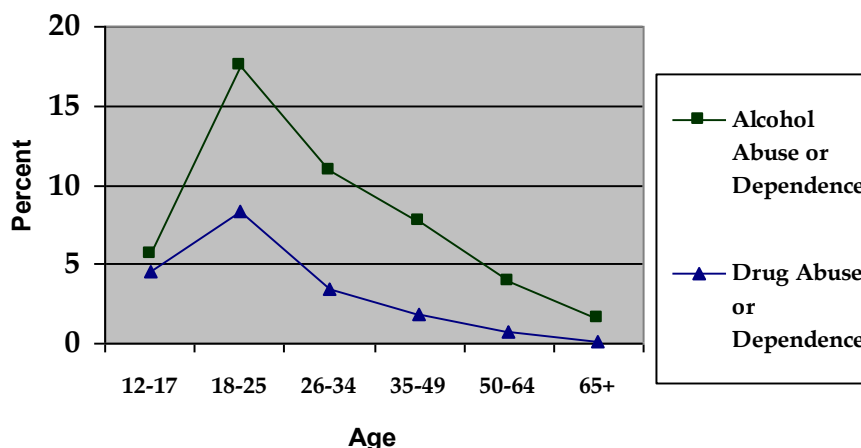
Although the NSDUH does not supply Missouri estimates of SPD specific to older adults, national estimates were available. According to the 2005 NSDUH, an estimated 4.6% of older adults experienced SPD in 2005. This is much lower than the Missouri SPD average of 12.8% for all adults older than age 26. Applying the national rate of 4.6% to the Missouri elderly population yields approximately 35,566 elderly Missourians with SPD.

However, although the rate of SPD among the elderly is low, there is still reason to be concerned about mental illness among the elderly. First, the prevalence of mental illness among the elderly may be higher in certain settings. For example, recent study of elderly Missourians in long-term care found that 6 percent of older adults had major depression and 19% had sub-threshold depression, of which 40% were persistently depressed over a one-year period (Missouri Senior Report, 2006). Second, research indicates that elderly individuals are very likely to under-report mental illness (Missouri Senior Report, 2007). Since the NSDUH relies on self-report, this is a methodological issue that may have resulted in an underestimate of elderly SPD in the NSDUH sample. Third, suicide rates are high among the elderly. The suicide rate of Missourians 65 years and older is the highest rate of any age group, while the rate for Missourians 85 years and older is twice the national average (CDC 1999). Overall, elderly suicides account for approximately 18% of all suicides (Missouri Suicide Prevention Plan, 2004). Furthermore, approximately 70% of seniors see their primary care physician in the month before they commit suicide (Miller and Druss, 2001). Finally, research suggests that individuals with serious mental illness may die up to 25 years earlier than the general population, often due to preventable medical conditions such as heart disease and diabetes (Parks, Svendsen,

Singer, Foti, and Mauer, 2006). This statistic illustrates the importance of considering mental illness within the framework of overall health and wellness.

Finally, the proportion of the population aged 65 and older will increase dramatically over the next few years. According to the 2000 U.S. Census, elderly individuals made up approximately 13.5% of the Missouri population. However, according to population projections consistent with the 2000 Census, the elderly population is expected to grow by 546,335 individuals between 2000 and 2030 (U.S. Census, 2005). Therefore, while the percentage of all elderly individuals experiencing mental distress may remain small, the proportion of the total population that is elderly and experiencing mental distress is expected to increase dramatically over the next 15 years. Since elderly Missourians make up a larger percentage of the population in rural areas, lack of transportation is likely to be among the largest barriers to accessible services for elderly Missourians in distress.

National Rates of Alcohol and Drug Abuse or Dependence by Age, 2005



Source: National Survey on Drug Use and Health, 2005.

Alcohol and Illicit Drug Use and Abuse

State estimates of alcohol and illicit drug use for those 65 and older are not available, but national rates of alcohol and drug abuse and dependence have been published. As can be seen in the figure above, rates of alcohol and illicit drug dependence decrease steadily throughout the lifespan, and reach their lowest rate among the elderly. In 2005, only 0.1% of older adults experienced illicit drug abuse or dependence at some point during the year (Wright, Sathe, & Spagnola, 2007); this percentage includes prescription drug dependence). Approximately 1.6% experienced alcohol abuse or dependence (Wright, Sathe, & Spagnola, 2007)). Application of those percentage to 2005 U.S. Census population estimates yields 773 elderly Missourians addicted to drugs and 12,371 addicted to alcohol in 2005. However, as mentioned previously, seniors are likely to underreport mental health issues, so it is possible that these numbers are underestimates.

Co-occurring Mental Illness/Substance Use Disorders

State data on the percentage of Missouri elderly experiencing co-occurring alcohol or substance dependence and SPD are not available, but nationally an estimated 0.2% of elderly individuals

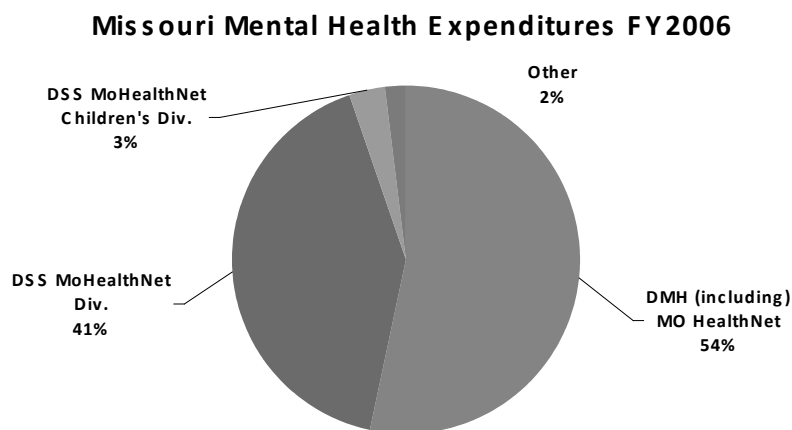
(approximately 1,546 Missourians) experienced co-occurring SPD and alcohol or drug dependence in 2005(Wright, Sathe, & Spagnola, 2007). This is compared to an average of 2.3% for all age groups.

Mental Retardation/Developmental Disabilities

State rates of mental retardation/developmental disabilities specific to the 65 and older age group are not available. However, based on the disability supplement of the NHIS 1994/1995, national rates were available for elderly adults age 65 and older. Approximately 0.4% of the elderly population experienced mental retardation and/or developmental disabilities in the NHIS sample. Application of that percentage to 2005 U.S. Census population estimates for Missouri yields approximately 3,093 Missourians aged 65 and older with mental retardation/developmental disabilities.

Financial Expenditures and Consumer Profiles

In FY 2006, the State of Missouri spent at least \$2.07 billion on mental health services. Over half of these expenditures (\$1,107,734,479), serving 144,644 consumers, flowed through DMH. The agency with the next largest percentage of total mental health expenditures (41%) was the MO HealthNet (Medicaid) Division Fee for Service (\$854,884,180) within the Department of Social Services, serving 305,566 consumers. MO HealthNet Children's Services Division's Comprehensive Psychiatric Rehabilitation program accounted for \$68,979,703 in expenditures. All other state agencies reporting at the time of this analysis made up the final two percent of expenditures, or \$40,019,141. The following section details these expenditures, profiles consumers and examines the needs met through state departments. Note: In addition, MO HealthNet Managed Care (MC+) spent \$895,336,173 in 2006 and some portion of that was spent on behavioral health which is not included in the figures above.

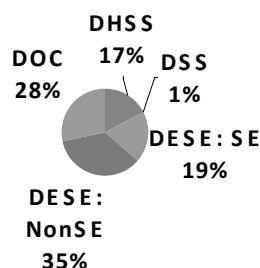


Consumer and Expenditures in Other State Departments

DMH and MO HealthNet serve the highest percentage of consumers of mental health care currently being served by state departments. Consumer numbers were not available for other departments at the time of this writing given difficulties in discerning mental health costs from other health-related costs. The task of discerning these costs will be undertaken next year and reported in the expanded version of the needs assessment.

Expenditures for these agencies included the Department of Corrections (DOC) (\$11,336,974)¹⁵, the Department of Health and Senior Services (DHSS) (\$6,845,406), the Department of Social Services (DSS) (non-MOHealth Net) (\$200,368)¹⁶, the Department of Elementary and Secondary Education's (DESE) Supported Employment (SE) expenditures (\$7,534,376), and DESE's non-SE expenditures (\$14,102,017). Expenditures from the Department of Public Safety were reported to be zero for FY2006; expenditures for the Office of State Courts could not be identified in time for this report.

**Other (2%) Mental Health Expenditures:
Non-DMH, Non-MO HealthNet**



Key:

DOC – Department of Corrections

DHSS – Department of Health and Senior Services

DSS – Department of Social Services

DESE: SE – Department of Elementary and Secondary Education: Supported Employment

DESE: Non-SE – Department of Elementary and Secondary Education: Non-Supported Employment

Additional Considerations

Mental health service needs vary by socioeconomic group. The state system primarily serves individuals unable to pay for insurance themselves, or who lack insurance through employment or other sources.

Department of Mental Health

¹⁵ The Missouri Department of Corrections (DOC) had expenditures of \$8,836,974 for substance abuse services including \$8,013,869 for prison and \$823,105 for community-based services. The DOC transferred \$3,541,048 to the DMH for community-based substance abuse services. The DOC also reported \$2,500,000 in mental health-related pharmacy expenditures. However, the DOC contracts for Mental Health Services in prison could not be identified; in FY2006, the costs of mental health and medical services were combined in one contract and could not be differentiated. The DOC did not provide community mental health services in FY2006.

¹⁶ The Missouri Department of Health and Senior Services (DHSS) had expenditures of \$6,845,406 for behavioral health related services including \$60,000 for Bright Futures; \$485,406 for Alcohol, Tobacco and Other Drug Prevention and Awareness Program; \$2,200,000 for Comprehensive Tobacco Use Prevention Program; and \$4,100,000 for Ryan White HIV Prevention.

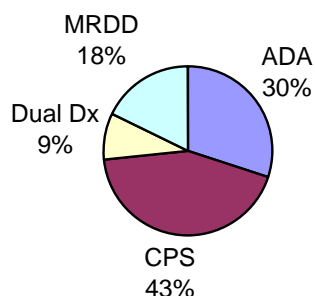
Consumer Profiles

DMH is Missouri's public mental health authority and, in FY 2006, served approximately 158,000 people statewide last year in its three divisions. (Note: the preceding number is a duplicated count because individuals may be served by one or more divisions.)

- 53,000 Division of Alcohol and Drug Abuse (ADA)
- 75,000 Division of Comprehensive Psychiatric Services (CPS)
- 30,000 Division of Mental Retardation and Developmental Disabilities (MR/DD)

In the same year, DMH served 144,644 unduplicated consumers including (a) 43,531 (or 30%) received substance abuse services, (b) 62,377 (or 43%) received psychiatric services, (c) 25,892 (or 18%) received mental retardation and developmental disability services, and (d) 12,844 (or 9%) received dual disorder services. Another 19,095 consumers were served by ADA's Substance Abuse Traffic Offender Program (SATOP) who are court-ordered to attend DWI classes at their own expense.

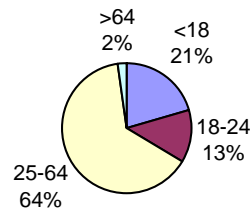
FY 2006 DMH Consumers Served



Note: Figure above includes consumers funded from all sources including General Revenue, Federal, and MO Healthnet.

Age and Race/Ethnicity of DMH Consumers. A majority of consumers were adults between the ages of 25 through 64 (64.1%), followed by children/youth less than 18 years of age (20.5%), transitional youth 18 through 24 years of age (13.1%), and the elderly (greater than 64 years of age) (2.2%). More males (57.8%) were served than females (42.2%).

FY 2006 DMH Consumers by Age



Note: Figure above includes consumers funded from all sources including General Revenue, Federal, and MO Healthnet.

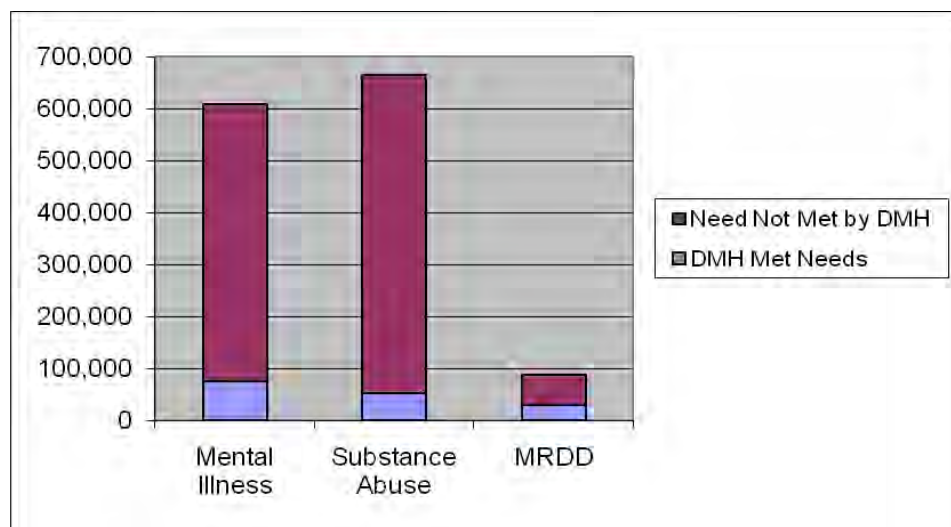
Around three-fourths (75.2%) of consumers were White, 20.5% were African-American, and 4.3% were of other racial or ethnic groups. The racial/ethnic makeup of the general population in Missouri is 85.4% White, 11.5% African-American, and 4.4% of other racial/ethnic groups.

Needs Met by DMH

The figure below depicts the mental health needs of Missourians met by DMH, estimated by using prevalence data and the numbers of consumers served by DMH. The needs met by DMH represent the numbers of consumers served in FY 2006.¹⁷ For persons with mental illness, approximately 12% of treatment needs were met by DMH, although a large number of individuals who did not receive services through DMH may have been served through other means. Around 5% of individuals with substance abuse difficulties (alcohol or drugs) were treated by DMH. DMH meets the needs of approximately 34% of people with mental retardation/developmental disabilities.

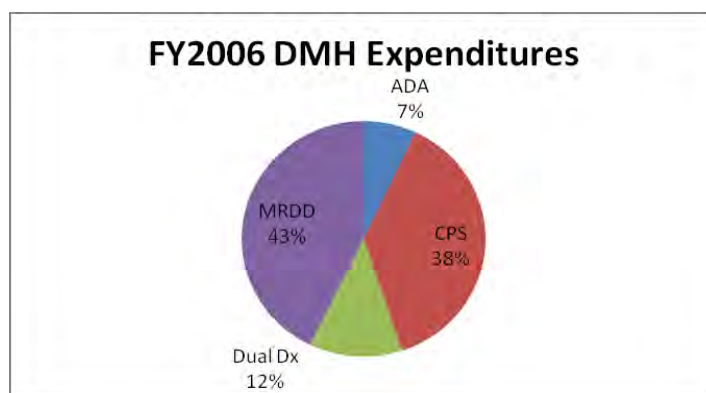
¹⁷ To provide comparisons with the duplicated prevalence counts described earlier in this chapter, numbers in this bar graph are duplicated counts as well and meant to approximately the treatment needs met by the Department of Mental Health.

Estimated Number of Missourians with Mental Health Needs and the Number Served by the Department of Mental Health



DMH Expenditures

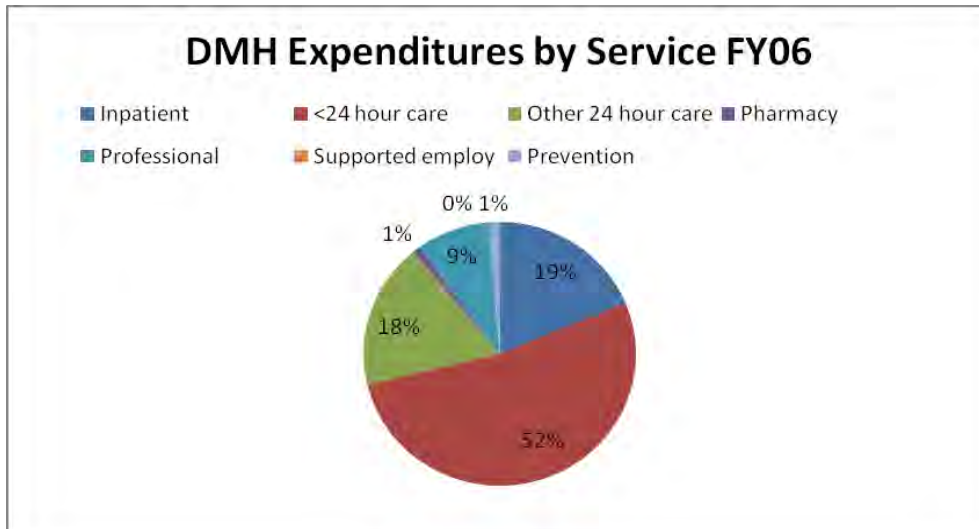
DMH provides services for persons with substance abuse, psychiatric and MR/DD disorders. In FY2006, most expenditures were for persons with psychiatric or mental retardation and developmental disabilities disorders. Specifically, \$77,878,614, or 7% of funds were expended for substance use services, \$419,655,616, or 38% were expended for psychiatric services, \$473,541,393, or 43%, were expended for mental retardation and developmental disabilities services, and \$136,658,852, or 12% was expended for persons with dual diagnoses. Any person served in FY2006 by two or more divisions of the DMH is counted in the dual disorders category.



Note: Figure above includes consumers funded from all sources including General Revenue, Federal, and MO Healthnet.

Expenditures by Type of Service. DMH expenditures supported a variety of services including (a) inpatient care (\$207,026,652), (b) less than 24 hour care, including acute care treatment (\$582,683,618),

(c) other 24-hour care, including community supported housing, respite care, residential detoxification, crisis stabilization, and other community services (\$196,846,024), (d) pharmacy costs (\$10,515,209), (e) professional services (psychiatrists, psychologists, social workers, etc. (\$96,308,323), (f) supported employment (\$420,058), and (g) prevention (substance abuse, suicide prevention) (\$13,934,594). The majority of costs were for less than 24 hour care. The fewest expenditures were for prevention services and pharmacy costs.¹⁸



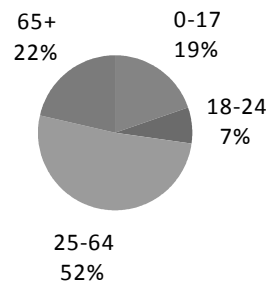
MO HealthNet

Consumer Profiles

A large percentage of consumers of mental health care in Missouri are served through the MO HealthNet Division (Medicaid). In fiscal year 2006, a total of 305,566 consumers were served either through the MO HealthNet Division (301,490 consumers) or the Children's Division (4,076 children and youth). Exact percentages by type of mental health problem (substance abuse, mental illness and MR/DD) will be available in future updates.

Of the consumers served through the MO HealthNet division, 59,983 (19.6%) were under 18, 22,404 (7.5%) were 18 to 24 years of age, 156,974 (51.4%) were 25 to 64 years of age, and 65,597 (21.5%) were 65 years of age or older.

Age of DSS MO HealthNet Consumers



Note: Figure above does not include MC+ and DMH MO HealthNet

Needs Met by MO HealthNet

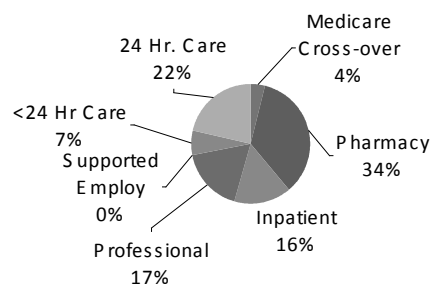
The availability of MO HealthNet funds substantially lessens the overall treatment gap in Missouri, filling around 23% of the total mental health needs in Missouri. Given that DMH serves around 10% of Missourians with mental health needs, these two funding sources together provide the ability to serve around one-third of those in need.

MO HealthNet Expenditures

Forty-six percent (\$963,883,024) of mental health-related expenditures flowed through agencies other than the DMH. Most of these expenditures were Medicaid expenses that flowed through the MO HealthNet (Medicaid) Division for general Medicaid expenditures and the Children's Services Division for Children's Psychiatric Rehabilitation services. In FY2006, MO HealthNet expenditures supported these services: (a) inpatient (\$143,857,429); (b) less than 24 hour care (\$61,400,069); (c) other 24 hour care (\$198,871,395); (d) pharmacy (\$323,174,514); (e) professional (\$160,390,099); (f) supported

employment (\$76,782); and (g) Medicaid costs associated with individuals who are both Medicaid and Medicare eligible (or Medicare cross-over costs) (\$36,093,594).

MO HealthNet Expenditures by Service FY06



Note: Figure above does not include MC+ and DMH MO HealthNet

Estimates from the Economic Research Division of the U.S. Department of Agriculture placed the Missouri 2006 poverty rate at 13.6%, resulting in 788,842 Missourians below the poverty line. The rate of mental illness in this population is greater than the general population. The rate of substance abuse among Missouri poor, while not as drastic as the rate of mental illness, is still estimated to be 10% greater than that of the general population (Maukish et. al., 2001).

Summary

This chapter has outlined the prevalence of mental health issues in the state of Missouri, and described the number of consumers and related expenditures served by DMH and MO HealthNet, the two largest providers of mental health care among Missouri state agencies. It has also begun to explore expenditures and consumers of services within other state departments. Next year's expansion of the needs assessment will explore this issue further by assessing the prevalence of mental illness among poor Missourians and the number of low-income Missourians served by the state system.

CHAPTER TWO: NARI KEY THEMES

The Missouri Institute of Mental Health (MIMH) researchers identified more than twenty overarching themes that emerged from the review of existing literature and Needs Assessment and Resource Inventory (NARI) data collection and analysis. These themes are clustered into six domains: (1) Safety; (2) Access to Care; (3) Mental Health Wellness; (4) Consumer-direction and Empowerment; (5) Quality Mental Health Care; and (6) Mental Health System Fragmentation. A listing of the key needs organized according to stakeholder group is provided at the end of the chapter.

Safety

The Transformation Initiative articulates a vision that Communities of Hope throughout Missouri will support and sustain a system of care where everyone at any stage of life has access to effective treatment and supports essential for living, working, learning, and participating fully in the community. The foundation for building this must be safety. Thus, an overarching goal embraced by the Transformation team is creating a safe environment for consumers of mental health services. The Quality of Health Care in America Committee of the Institute of Medicine (IOM) in their landmark report *“To Err is Human: Building a Safer Health System”* concluded that harm caused by the health care system is unacceptable, and the delivery system should “First, do no harm.” (IOM, 1999) The NARI identified four primary issues related to safety where there is a documented need for system reform: (1) abuse and neglect; (2) trauma; (3) preventable medical errors; and (4) occupational safety.

Abuse and Neglect

Regardless of the type of disability or whether the abuse is emotional, physical, or sexual, research has demonstrated that people who provide care and support to individuals with disabilities are often the same people who victimize them – people the victims know and trust (Petersilia et al., 2001; Nosek et al, 1997; Marchetti & McCartney, 1990). This is true whether those who are the targets of abuse and neglect live in facilities or in the community.

In large part, the needs related to institutional abuse and neglect in Missouri’s mental health system have been recently addressed in response to incidents in habilitation centers that rose to the public’s attention in 2006. Missouri Governor Matt Blunt responded to public concern by appointing a Mental Health Task Force (MHTF), whose charge was to review best practices and make recommendations for changes to the mental health system to improve safety for consumers. A series of public hearings were held at six locations across the state where over 300 Missouri citizens spoke about their

concerns. The MHTF issued its report in November, 2006, describing 25 action steps for improving consumer safety. Key action steps included: (1) recruiting and retaining staff by offering more competitive pay; (2) improved staff training; (3) centralized data collection and analysis capabilities; (4) leadership stability; and (5) and systemic reforms around abuse and neglect reporting.

In December 2006, Governor Blunt issued an Executive Order directing safety-related action by the Missouri Department of Mental Health (DMH). Subsequently, mental health reform legislation (SB 3) was passed by the Missouri legislature that incorporated many of the key recommendations of the MHTF and the Commission. Additional details about the series of steps and activities undertaken and the progress to date are fully documented in the final report (Missouri Mental Health Task Force, 2006)

From these reports, 25 action steps for improving consumer safety emerged, including: (1) recruiting and retaining staff by offering more competitive pay; (2) staff training; (3) centralized data collection and analysis capabilities; (4) leadership stability; and (5) abuse and neglect reporting; and (6) accreditation. Many of these actions steps have been completed; remaining steps include:

1. National accreditation of mental retardation/development disabilities habilitation centers;
2. Hotline ties between Department of Health Senior Services (DHSS) and Department of Social Services (DSS);
3. Salary enhancement for direct service staff;
4. Standardized training for consumer, families and staff to identify and report abuse and neglect;
5. Licensure redesign;
6. Legislation and regulation amendment for administrative actions, fines for failure to implement;
7. Background checks on new employees;
8. DMH Fatality Review Board;
9. Review and revise DMH MOU with Missouri Protection and Advocacy Services;
10. Public access to non-confidential information in final reports of substantiated abuse and neglect; and
11. Triage of incidents for joint investigation of all deaths or near deaths that are suspect for abuse and/or neglect. (Missouri Mental Health Task Force, 2006)

While institutional abuse and neglect has garnered attention recently, much abuse, neglect and exploitation also occurs in the community. People with disabilities may suffer from and be victimized by acts of abuse and neglect wherever they live. Community-based abuse and neglect is an important safety issue that will be explored more fully in the next NARI.

Trauma

Increasing attention has been paid to the inter-relationship between psychological trauma and psychiatric and substance abuse disorders. With this recognition has come an awareness that existing public mental health systems are not adequately prepared to help victims of trauma. Nationwide, mental health systems lack screening and assessment procedures for trauma identification, staff training on properly understanding trauma, information about trauma-related evidence-based

practices, and trauma diagnostic skills—all of which, lead to poorer treatment outcomes (Salasin, 2007).

Recognizing the seriousness of psychological trauma to consumer health, the DMH has recently introduced programs and policies to create a more trauma-informed system of care. Programs have included trauma training, development of a policy statement regarding trauma, and a Trauma Screening Program for Children.

While these efforts serve as a good start toward developing trauma-informed care, there is nonetheless a strong need for additional efforts in this area. A system of assessment for trauma-informed care with a formal plan of action has been suggested as a method to move away from fragmentation, towards a coordinated system of care for trauma victims.

In addition to addressing the needs of those entering the public systems with psychological trauma, there is also a significant need to address possible traumatization of individuals once they have entered the public system of care. In the daily care of individuals needing services, the potential for inducing trauma can arise, and in the past, some of the policies created to address consumer behaviors have been trauma-inducing. Examples of this include: restraint and seclusion methods used to prevent violent acts, and psychological trauma induced by treatment providers without appropriate trauma training who unwittingly traumatized consumers during the treatment process.

To address trauma resulting from restraint and seclusion, DMH is currently providing training on alternatives to restraint and seclusion at Fulton State Hospital, an intermediate and maximum-security forensic mental health care hospital. This training curriculum has been a significant first step toward the implementation of a comprehensive statewide plan to provide alternatives to restraint and seclusion. Learnings from the Fulton State Hospital project have been shared in training with all of the state-operated psychiatric and habilitation facilities. Further training programs throughout the state hospital system are needed, as well as statewide policies providing alternatives related to trauma sensitivity and trauma treatment. Additionally, more training of treatment providers on the effects of trauma on their clients is warranted.

Preventable medical errors

Nationally, an estimated 44,000 to 98,000 people die each year as the result of preventable medical errors. Adverse drug effects, surgical injuries, restraint-related injuries, falls, burns and mistaken identities are all types of medical errors which, when added together, exceed the number of deaths from motor-vehicle accidents, breast cancer and AIDS (IOM, 1999). Specific errors include errors in diagnosis and treatment, failure to use indicated tests, medication and dosage errors, delays in treatment, inappropriate care, inadequate monitoring, communication, equipment and other system failures.

The Division of Comprehensive Psychiatric Services (CPS), DMH, does not document all medical errors, but does document medication errors. Medication errors refer to inappropriate prescribing, distributing, administering, or monitoring of medications by CPS staff. There were 854 documented medication errors in 2007. Many of the mental health consumers participating in focus groups stated that there was a need to better monitor their care. They also reported errors and delays in the

diagnosis of their mental illness. The current safety plan developed in the past year addresses some of these concerns through additional staff training. Required preventable medical error training for all providers working with consumers should be a consideration.

Occupational safety

Bureau of Labor Statistics data show that in 2000, 48 percent of all non-fatal injuries from occupational assaults and violent acts occurred in health care and social services. Most of these occurred in hospitals, nursing and personal care facilities, and residential care services. Nurses, aides, orderlies, and attendants suffered the most non-fatal assaults resulting in injury.

Data from CPS indicate that Missouri has safety issues comparable to those in other states. In 2007, in-patient facilities reported 978 staff injuries, most of which occurred in the intermediate and maximum security forensic hospital. As described above, significant efforts are being exerted at Fulton State Hospital to address both client and staff safety through existing grant funds. Furthermore, as outlined in the Annual Safety Report, improving staff working conditions in DMH-run facilities is a high priority, and additional staff training on how to work with clients to avoid injury should be a priority.

"Even if you know where to go for help, there are just long waiting lists.....there is not access to services right away." (Parent)

Access to Care

Lack of information about mental health, embarrassment about seeking care, and belief that mental illnesses can be addressed without treatment are some of the many reasons that persons needing help do not seek services (Sale, Patterson, Evans, Kapp, & Taylor, 2007). But for those who want to get help, significant barriers impede their ability to access quality care in a timely manner. Data collected for the NARI strongly suggest that the following issues related to access are significant impediments to obtaining services:

- (1) Provider shortages, including child and geriatric psychiatrists and providers skilled in addressing co-occurring disorders;
- (2) Inpatient Psychiatric Bed shortages;
- (3) Lack of affordable services;
- (4) Lack of adequate transportation, especially in rural areas;
- (5) Housing and employment shortages;
- (6) Cultural disparities; and
- (7) Limited specialized services for children, transitional youth, and the elderly.

Provider and Bed Shortages

Provider Shortages

The shortage of mental health professionals and providers has been well documented. Nationally, the number of providers is especially low in rural areas, and there are shortages for children and older adults (Hanrahan & Sullivan-Marx, 2005; U.S. Department of Health and Human Services, 1999). Furthermore, there is a severe shortage of trained professionals to address the mental health needs of those with substance abuse and co-occurring disorders. The shortage of providers serving the needs of low-income persons is even greater.

89% of substance abuse and mental health care providers reported a high or critical need for out-patient co-occurring disorder providers.

As of 2004, only eight states in the nation have fewer psychologists than Missouri (population adjusted). Missouri fares better with the number of psychiatrists (16th in the nation) and social workers (19th). There are a total of 410 psychiatrists, 1,330 psychologists and 10,680 social workers reside in the state of Missouri. Adjusted for the population of Missouri, this amounts to 7.12 psychiatrists, 23.11 psychologists and 185.59 social workers for every 100,000 persons (New York Center for Health Workforce Studies, 2006). In Missouri, as of 2001, there were only 101 child psychiatrists, or 7.1 per 100,000 population. If true transformation of the mental health system is to occur, the number of mental health care professionals will need to expand to meet the greater demand for services.

Missouri Licensed Mental Health Service Providers, 2004

Professional	Number	Average Number Per 100,000 Population	U.S. Avg. Per 100,000 Population	Ranking
Psychiatrists	410	7.12	5.21	16
Psychologists	1,330	23.11	33.52	42
Social Workers	10,680	185.59	158.27	19

All data sources consulted for the NARI indicated that there is a significant need for providers in Missouri. In particular, specialized providers, particularly psychiatrists, and mental health professionals addressing co-occurring disorder needs are in need according to several groups, including consumers and agency staff. Many of the Division of Mental Retardation/Developmental Disabilities (MR/DD) providers felt that some provider shortage issues could be addressed with better coordination across different agencies within the state system.

- 89% of all substance abuse and mental health providers felt that there was a high or critical need for co-occurring disorder out-patient providers.

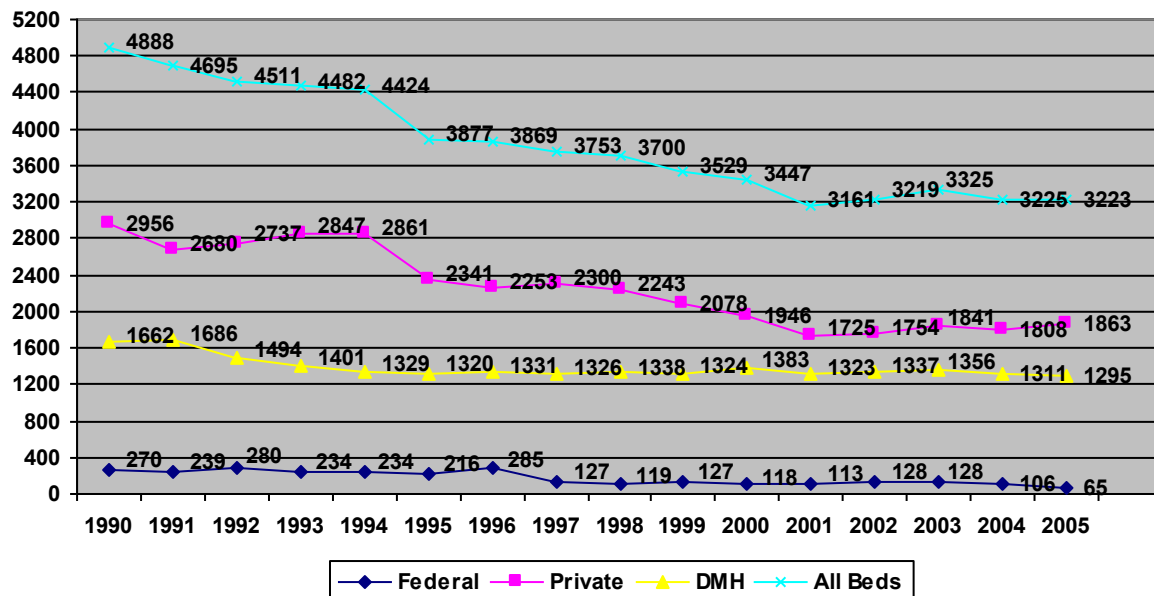
- Almost 70% of substance abuse and mental health providers expressed a high or critical need for more psychiatrists.
- Approximately 63% indicated a high or critical need for more geriatric specialists, and
- 54% wanted more child specialists.

Almost 70% of substance abuse and mental health providers expressed a high or critical need for more psychiatrists; 63% indicated a need for more geriatric specialists, and 54% needed more child specialists.

In addition, focus group members expressed the need to expand the workforce to include more geriatric psychiatrists, child psychiatrists, interpreters and providers trained to work with the deaf and hearing impaired, international, African-American, immigrants and refugees and Hispanic consumers.

Finally, many focus group members felt that mental health support and information could be obtained from “natural” community caretakers, including members of the faith community and nursing home personnel, provided that they were adequately trained in mental health care. They could then serve the role of providing more information to the community, help to reduce stigma and encourage accessing mental health services. Improved community crisis services so that they are able to provide immediate services to those in crisis were expressed as a need by several focus group members.

Federal, State and Privately Staffed Psychiatric Beds 1990 - 2005¹



Service and Bed Shortages

The state mental health system delivers services to hundreds of thousands of individuals each year through its direct service system and MO HealthNet-financed services. Nonetheless, there is a shortage services as evidenced by waiting lists and the declining number of staffed psychiatric beds.

According to data provided by the MR/DD, in January 2008, there were 3,629 individuals on waiting lists for in-home services and 393 on the waiting list for MR/DD residential services. While waiting list data were not available for those needing substance abuse and psychiatric services, high use of emergency room facilities indicate a lack of community service capacity.

Because of a dramatic decline (1,665) in privately and federally-funded beds between 1990 and 2005, the demand for state-funded beds continues to increase, with DMH beds now equaling 40% of all beds (2005) compared to 34% in 1990 (DMH, 2008). Mental health, substance abuse and MR/DD providers listed more inpatient and residential care as a major need, especially for persons with co-occurring substance use/mental disorders. This need was reinforced by focus group consumers. MR/DD providers especially expressed the need for better behavioral management services in inpatient facilities. Correcting this lack of inpatient and crisis beds was a particularly strong need for persons participating in rural focus groups, who reported traveling long distances to reach hospitals with psychiatric beds.

Lack of Affordable Services

Over the course of a year, three-fifths of people with severe mental illnesses do not receive specialty care. Lack of insurance and ineligibility for Medicaid services contributes to the problem. In the United States, one in five people with severe mental illness lack health insurance and only 37% of people with severe mental illness are covered by Medicare or Medicaid (NAMI Fact Sheet; 2004). According to a recent study by the Lewin Group, in 2007, an estimated 587,271 Missourians (or 10.1%) do not currently have health insurance or MO HealthNet coverage. The majority of these individuals make less than 300% of the poverty level (436,764). Around 44,000 uninsured Missourians are children 18 and under. (Lewin Group, 2007)

Across the board, the affordability of services was a predominant theme among Missouri stakeholder groups. Eight of the 10 focus groups held as part of the NARI identified affordability as a major issue, pointing to MO HealthNet restrictions as a significant impediment to obtaining care. These groups included the elderly, African-Americans, rural residents, homeless persons, transitional youth, refugees and immigrants, and persons on probation or parole. Transitional youth often age out of children's services with no financial means or steady employment to provide them with health insurance. Prisoners transitioning to the community found several barriers to reinstating insurance upon reentry and the homeless often found endless bureaucracy gets in the way of receiving public assistance.

Transportation

Transportation is consistently cited as a major barrier to accessing care nationwide, particularly in rural areas. In a study of health care utilization, it was found that individuals with their own transportation made significantly more health care visits than did people who had to rely upon public transportation or others forms of transportation (Arcury, Preisser, Gesler, and Powers, 2005).

Transportation consistently was identified as a top need for providers and consumers consulted for the NARI. It was perceived to be a high or critical need among almost 90% of mental health care and substance abuse agencies. Among MR/DD providers, transportation emerged as the fourth most needed services. Transportation was a major problem for individuals in five of the ten focus groups, particularly those in rural areas. Elderly individuals who could not drive were in need of mobile services and youth in rural areas reported needing transportation to drive to the closest service providers, which are often in metropolitan areas. Transportation was a huge issue for the homeless, who have difficulty getting services and gaining employment without reliable transportation. Hispanics also reported that lack of transportation makes it less likely that they would seek services. Telehealth and in-home services were suggested as ways to provide services in rural areas which would alleviate the demand for transport. However, the provision of services in rural communities would be ideal.

Transportation was perceived to be a high or critical need among almost 90% of mental health care and substance abuse agencies.

Housing and Employment

Persons with substance abuse, mental illness and MR/DD face significant challenges in finding adequate housing and employment. It is estimated that the unemployment rates for persons with serious mental illness range from 70-90%, and that persons with disabilities have unemployment rates that are double those of the general population. It is also estimated that on any given night, 175,000 persons with serious mental illness are homeless. (U.S. Census Bureau, 2000; SAMHSA, 2004)

Considerable efforts are in place to provide housing and employment opportunities for consumers served by the state system. Housing supports include Supported Community Living, Housing and Urban Development (HUD) Shelter Plus Care grants, a housing registry accessible to all but originally initiated by MR/DD, Home and Community-based Services (HCBS), and many others. Employment supports include, but are not limited to Supported Employment programs, vocational rehabilitation programs, Project Success, Integrated Dual Diagnosis and Treatment Programs (IDDT), and Assertive Community Treatment programs. Information gathered by MIMH via surveys and focus groups indicate an even greater need for these services, particularly among MR/DD providers. These providers cited shorter waiting lists, and affordable and handicapped accessible housing as very high needs. Almost 80% of MR/DD providers expressed a need for more employment opportunities and better paying jobs. These needs were echoed by focus group members.

Shorter waiting lists for housing was the number one need for providers of care for persons with MR/DD.

Age-Specific Disparities

Children and Youth

From focus groups held in Missouri in 2003 to formulate a shared agenda for children's mental health, the following issues were identified as barriers to children needed mental health treatment: (1) adequate communication and collaboration; (2) stigma of mental illness; (3) training in the area of mental health; (4) family respect and support; (5) support for children inside and outside the school setting; and (6) support for schools (Shared Agenda, 2003). In addition, limited resources and provider shortages are also barriers to receiving care. Parents may have insurance plans that limits mental health and substance abuse treatment. Lower income parents may not qualify for MO HealthNet or the State's Temporary Aid to Needy Families (TANF) Health Insurance Program (MC+).

A lack of providers specifically addressing children's mental health is a serious issue both nationwide and in Missouri. Numerous studies have concluded that there is a severe shortage of child and adolescent psychiatrists in the United States (U.S. Department of Health and Human Services, 1999). This shortage is compounded by an inequitable distribution of child and adolescent psychiatrists such that children living in poverty or rural areas are least likely to have access to child and adolescent psychiatrists (Thomas & Holzer, 2006). In Missouri, as of 2001, there were only 101 child psychiatrists, or 7.1 per 100,000 persons.

To better address the needs of children and improve collaboration across state departments, the Comprehensive System Management Team and the Office of Comprehensive Child Mental Health were legislatively formed in 2006. Other significant efforts include expanded prevention efforts for children and youth, recommendations for statewide expansion of school-based mental health providers, and continued expansion of the System of Care programs addressing the needs of children. Transformation Work Group recommendations include promotion of protective factor prevention models, mental health consultation in early childhood and school settings, and the statewide development of the Missouri School-based Mental Health Model.

Transitional Youth

While transitional youth make up a relatively small percentage of the overall population, this age group is particularly vulnerable to alcohol and drug abuse. Transitional youth also represents an age group when many mental illnesses begin to present themselves. These characteristics accentuate the need for significant services. However, as these youth are transitioning from child to adult systems of care, services may, in fact, be cut. When youth age out of childhood services, including special education, child welfare and juvenile justice systems; they are often neglected (Davis and Vander Stoep, 1997; Davis 2003). Among transitional youth in Missouri these difficulties are compounded further by a lack of government assistance (few qualify for MO HealthNet and the SCHIP program discontinues at age 19) in a population that is largely uninsured--29% of women and 37% of men aged 21-24 were uninsured in 2006 (Fronstin, 2007).

One significant barrier to accessing care has been recently rectified. In 2007 foster children remained eligible for MO HealthNet until age 21, allowing for continued health care funding for this narrow

band of transitional youth. A large majority of transitional youth will continue to fall through the cracks as they try to maneuver through a complicated treatment system.

The Elderly

“The current generation of older persons still views mental illness as a “personal flaw”, not an illness that can be successfully treated.”
(Interview with Area Agency on Aging Director)

Mental illness is a significant issue for older adults. As individuals age, factors such as chronic illness, institutionalization, isolation, and grief can lead to depression and other mental illness. These factors are also associated with an increased risk for suicide.

Barriers to appropriate older adult mental health treatment include: low MO HealthNet reimbursements, lack of training among primary care physicians, few geriatric psychiatrists, resistance to obtaining care, lack of recognition that seniors suffer from many types of mental illness, and lack of nursing facility staff training and knowledge of the mental health needs of residents. Based on three focus groups conducted with older Missourians (aged 65 and older) in both rural and urban areas, needs included: (1) reduction in stigma; (2) integration of physical and mental health care; (3) training of natural community supports; and (4) mobile services.

Cultural Disparities

African-Americans, Hispanics, deaf and hearing-impaired individuals, the homeless, immigrants and refugees, and lesbian/gay/bisexual/transgender individuals, all face unique barriers to receiving quality care. Major themes addressed by most focus groups with these individuals included: (1) stigma reduction; (2) public education about mental illness; (3) the need for culturally-similar and culturally-competent providers; (4) additional community supports; (5) translation of mental health information; (6) interpreter mental health care training; (7) additional community supports (housing, help finding care), and (8) training and education of the faith community on mental illness. Transformation Work Group members recommended that “everything that emanates from this Transformation Initiative be culturally/linguistically appropriate” (Transformation Work Group Recommendations, 2007).

Mental Health Wellness

Prevention and Early Intervention

Emerging evidence suggests that certain mental health problems can be prevented, while in others onset may be delayed and severity of symptoms decreased. Prevention efforts are most successful when they use multi-faceted solutions that address, not only individuals, but also their environments, including home, work, and school (Greenberg et al., 1999). Applying a primary prevention framework to mental health can support the care and treatment of those in need, while also reducing the stigma associated with mental health problems.

The deaf and hearing impaired, Hispanics, African Americans and immigrants/refugees all expressed the need for more culturally competent providers

(Institute of Medicine, 1999).

The NARI explored existing resources and expressed needs of stakeholders groups. Significant efforts have been made in the past several years to increase prevention and early intervention efforts in Missouri, including school-based substance abuse programming, after-school programs for youth, programming for pregnant women and young mothers, fetal alcohol awareness programs, systems of care initiatives, and delinquency prevention programs. Prevention and early intervention strategies can also be very effective with late-onset mental and substance abuse problems experienced by the elderly. There is a great need for expanded prevention programming.

Several stakeholder groups stressed the importance of prevention and early intervention. Among Transformation Work Group members, adoption of a public health model with a focus on prevention was listed as one of the top ten needs, followed by substance abuse education services and early intervention/screening. Among focus group participants, prevention programming for at-risk youth was particularly important, with many groups citing the need for more after-school programs for youth. Transitional youth, families with children and public hearing participants felt that mental health curricula should be placed in high schools, possibly as part of regular health classes. Public hearing participants cited the need to coordinate existing prevention plans and training providers on prevention strategies. Work group members recommended several prevention and early intervention strategies, including mental health screening, school-based mental health and curriculum development, expanded mobile services to address non-emergency situations, and expanded systems of care in local communities.

Stigma

Individuals with severe mental illness, substance abuse problems, or mental retardation and/or developmental disabilities are disparaged more often than persons suffering from physical illnesses (Corrigan et al., 2005; Fulton, R., 1999; Hinshaw & Cicchetti, 2000; Waldman, Swerdloff & Perlman, 1999). Stigma is not confined to the general population. Stigma among mental health professionals, the media, the faith community, primary care physicians, employers, and other professionals is equally or perhaps more pervasive.

Among mental health and substance abuse providers, expanded school-based mental health services was perceived to be a high or critical need (78%),

While stigma nationwide is well documented, the only recent study of stigma in Missouri relates to mental illness stigma. This study found that a high percentage of persons in the general population would be unwilling to work with someone with a mental illness or have someone with a mental illness marry into their family (Sale, Patterson, Evans, Kapp, & Taylor, 2007). Persons with schizophrenia, who many perceived to be dangerous, were most stigmatized. Stigma was strongest among males (particularly upper-income males), and the elderly.

While stigma has decreased over time, it is still a significant issue for a large number of adults living in Missouri. The TWG ranked “improving the public perceptions of persons with mental health needs” as the third most critical action to be taken to transform the mental health system. Stigma reduction was mentioned by *all* of the focus groups conducted for the NARI, with many stating that

stigma from the community and mental health staff was impeding recovery. Future considerations include an anti-stigma and public education campaign, with targeted messages to males and the elderly, and training of service providers, including mental and physical health providers, employers, and the faith community.

Public Mental Health Literacy

It is becoming increasingly evident that improving the public's level of knowledge regarding mental disorders (e.g., mental health literacy) is crucial for early recognition and intervention in mental disorders (Lauber, et. al., 2005; Kelly, Jorm, and Wright, 2007; Jorm, 2000). Knowledge about mental health is also an important determinant as to whether or not a person seeks help (Lauber et. al., 2005).

In Missouri, a recent survey on attitudes toward mental illness found that while a majority of respondents stated that chemical imbalances, genetics and stress are responsible for mental illness, 35% of respondents still thought that mental illness is likely to be caused by how the person was raised, almost 30% believed it was somewhat or very likely to be the result of bad character, and over 20% of individuals believed that mental illness was likely to be result of a higher power. A very high need for greater public mental health literacy efforts was expressed by mental health and substance abuse providers; 87% felt that public awareness and education were either high or critical needs. Anti-stigma campaigning, education of community professionals, youth training and creation of a peer speaker's bureau were suggested by Transformation Work Group members as ways of addressing public literacy issues.

Mental and Physical Health Integration

Often, the first point of contact for someone with a mental illness is their primary care physician, and in many areas where access to mental health care professionals is limited, the primary care physician may be the sole mental health care resource. However, many primary care physicians lack knowledge regarding the relationship between mental and physical illness, and how mental health issues can present themselves as physical health conditions.

Almost all (87%) mental health and substance abuse providers felt that public education and awareness were high or critical needs.

The critical relationship between physical and mental health care providers was noted by all stakeholder groups. Particularly in rural areas, where individuals rely more upon their physicians for all around care, physician education and/or strong linkages with a psychiatrist is needed. Stakeholders expressed the need to offer mental health care services in public health offices, move to collaborative care practices, encourage the use of technology to share records between mental and physical health care providers, and provide more education in medical schools on mental health care to help bridge the gap between physical and mental health care providers.

Consumer-directed Care and Empowerment

Consumer Decision Making in Care

A transformed consumer-driven system of care can be conceived of as one with consumers and their organizations at its hub, where consumers choose what they need from an array of services and supports (U.S. Department of Health and Human Services, 2005). According to the President's New Freedom Commission Report, this includes enhancing consumer choice in their treatment, supports, and funding for services (President's New Freedom Commission Report, 2006).

Consumer-driven care is a high priority need expressed by *all* groups, whether they were consumers, agency staff, workgroup members, or public hearing participants. Focus group members and public hearing participants believe they are not being heard in the current system and that they should be involved in the treatment decision-making process. Transformation Working Group members felt that consumer-driven care is a critical need and should be one of the first priorities taken in the transformation effort. Consumer-driven care was the third highest priority for MR/DD providers.

Consumer Recovery/Support Services

In addition to the housing, employment, transportation and provider needs discussed above, the need for additional recovery supports for consumers of mental health care were felt to be a strong need across all stakeholder groups. Provider agencies listed this as their 2nd most important need. Many focus group members, including transitional youth and rural consumers expressed frustration with the quality and accessibility of existing support services. Probationers expressed concerns that, after their release from correctional facilities, many support services are no longer available to them. Transformation Work Group members made several recommendations, including the expansion of evidence-based peer and family-run programs to help strengthen existing recovery and support services.

Consumer-run services and consumer-providers can broaden access to peer support, engage more individuals in traditional mental health services, and serve as a resource in the recovery of people with a psychiatric diagnosis. Because of their experiences, consumer-providers bring different attitudes, motivations, insights, and behavioral qualities to the treatment encounter (New Freedom Commission on Mental Health, 2003). Consumer organizations provide, within a non-stigmatizing environment, what the traditional mental health system cannot offer. They help integrate the fragmented services needed for recovery that span multiple systems of care, such as housing, employment, and social services. There are a number of organizations with consumer and family involvement in Missouri. Some of these have advocacy as their primary mission, some are primarily geared toward service, education and/or support, and others are affiliated with governmental agencies. As relates to traditional consumer/family member organizations, most have local geographic membership. In Missouri, several consumer-run organizations have regional or state-wide membership, including the National Alliance on Mental Illness (NAMI), Missouri Recovery Network, and MPACT (Missouri Parents ACT), Consumer-operated Service Programs (COSPs), drop-in centers and warm lines. However, expansion of these consumer-run organizations as well as

membership within current organizations was seen to be a way to help enhance existing recovery efforts across the state, particularly in rural areas where there are presently fewer recovery supports.

Quality Mental Health Care

Workforce Development

A well-trained workforce is an essential component to delivering high-quality mental health. However, the existing workforce lacks adequate training across a variety of areas, including mental health care promotion and prevention, training on trauma and co-occurring disorders, and training in the implementation of evidence-based practices.

The training needs in Missouri are similar to needs across the nation. According to recommendations that emerged from the recent Lieutenant Governor's Report on safety, "training may be the most important factor in ensuring that individuals with disabilities are protected" (Missouri Mental Health Task Force, 2006, p. 29).

As part of the NARI, MIMH explored workforce training issues with consumers and providers. The following needs emerged:

- **Co-occurring Disorder Training.** Among providers, there was a very high need expressed for training of direct staff in the area of provider co-occurring disorder training with **82%** of substance abuse and mental health respondents indicating that it is a high or critical need. Co-occurring disorders training and treatment ranked as the **#1** need that mental health and substance abuse agencies would advocate for if they could choose only one issue. Co-occurring disorder training was the fourth greatest need for MR/DD providers. The need for more co-occurring services is also a theme among focus group consumers.

[

82% of mental health and substance abuse providers expressed a high or critical need for co-occurring disorder training

]
- **Evidence-based Practices.** Almost three-fourths of providers felt that training in evidence-based practices was either a high or critical need.
- **Quality Care.** Many focus group members felt that their counselors did not have adequate skills to provide quality counseling services, relying upon medication for mental illnesses that could have been treated through therapeutic interventions. In some cases, individuals cite instances where medication administration resulted in negative outcomes. Consumers reported that when they experienced poorly trained counselors their trust with the counselor was destroyed, thereby preventing any positive therapeutic outcomes or recovery.

The training needs of the mental health workforce are being addressed currently in several ways:

- Standardized training for all DMH and provider staff on identifying and reporting abuse and neglect;
- Salary enhancement for direct care staff are on the current FY 2008 DMH agenda;

- Development of e-learning through the current Network of Care contract;
- System wide workforce development for children;
- Standardized prevention training for all direct service staff;
- Cultural competency training for substance abuse prevention providers to address gender, ethnic, educational and age diversity; and
- Prevention certification for all direct service substance abuse prevention staff

For future consideration, recommendations from the Transformation Work Groups included: (1) pre-service provider training on predictive factors, prevention strategies and other topics; (2) in-service training on behavioral health to schools, etc.; (3) professional training to support best practices and integrated care and teach professionals to be able to communicate effectively across disciplines and settings (effective “crosstalk”); and (4) educational and reimbursement incentives to increase health and behavioral health specialists in areas of need across lifespan.

Evidence-based Practices

Evidence-based practices (EBPs) in the mental health and substance abuse fields are those practices that have been demonstrated effective through experimental research. EBPs can refer to either the type of method used in delivering mental health care interventions, or to the specific treatment or services shown to have positive outcomes on the individuals receiving treatment. In the mental health field, evidence-based practices generally describe different therapeutic approaches (cognitive behavioral therapy, IDDT, etc.) (Hoagwood et al., 2001) or clusters of practices, such as Assertive Community Treatment (ACT) defines a particular way of delivering treatment.

In the mental health, mental retardation/developmental disabilities and substance abuse prevention and treatment areas in Missouri, there is a concentrated effort to move toward the use of EBPs though systems of measuring the fidelity of implementation of EBPs are only now beginning to be implemented. Recovery programs are also focused upon the use of EBPs, including the widespread use of emerging programs such as COSP.

In the NARI survey of providers, 82% of the substance abuse and mental health provider agencies reported using EBPs. Cognitive Behavior Therapy, motivational interviewing, and medication management were reported as used most frequently. Trauma Recovery and Empowerment Treatment (TREM), and Supported Employment, though used less frequently, were ranked most effective. Among MR/DD providers, Positive Behavior Supports and Person Centered Planning were used most often and were rated as either extremely or very effective by most agencies that use them. This survey made no effort to verify EPB service delivery.

The EBP Transformation Work Group developed the following recommendations: (1) interdepartmental approach (e. g., EBP Committee) to develop policies, regulations and financing strategies that support EBP; (2) policy statement that ensures broad-based consumer and family input into EBP funding; (3) systematic and collaborative approach to EBP education/training and outcome measurement; (4) provider financing incentives to support EBP development and practice; (5)

consumer choice of providers certified in an EBP by DMH; (6) establishing “Coordinating Centers of Excellence” (7) training curriculum and implementation process for EBP core competency development; (8) education and licensure incentives for continuing education in evidence-based practices; and (9) partnerships with colleges and universities to incorporate EBP into course curriculum and provide training opportunities in practice and implementation. Assessment of program fidelity and on-going monitoring of new evidence-based practices should also be a priority.

Quality Management

Using evidence-based practices goes a long way toward improving the quality of care delivered to persons in need of mental health care. Adding an expanded and well-trained workforce builds this capacity further. A third necessary ingredient to assuring excellence in care is the development of a quality management system that monitors and evaluates the implementation of evidence-based practices and maximizes the use of existing informational and technological resources to better coordinate care. Quality management includes the establishment of uniform quality standards, periodic assessment and evaluation of program activities to assure high quality implementation. The NARI identified a myriad of quality management procedures implemented to assure quality service delivery across departments involved in mental health care, including MR/DD Quality Control Measures, Quality Service Reviews and Medication Risk Management, third-party evaluations of several large-scale grants, and the development of standardized outcome measures. The Technology Transformation Workgroup identified a myriad of technological quality management resources currently in place across all seven departments involved in the delivery of mental health care. However, considerable work to further improve quality service delivery is needed.

Future considerations to improve quality management, as recommended by the Transformation Work Groups, included perhaps first and foremost the development of a unique consumer identifier across departments to improve treatment coordination for individual consumers. Additional recommendations included: (1) regular statewide training on EBPs; (2) Advanced Information Technology systems that fully integrate Quality Management databases; (3) systematic and comprehensive evaluation of department quality management procedures and programming; (4) Electronic Health Record (EHR) system owned by the consumer and shared with providers; (5) Electronic Medical Records system (EMR); (6) systematic data analysis. (7) outcome analysis; (8) e-based information sharing system; (9) e-based system for training; and (10) expanded teleconferencing to improve program monitoring and communication.

Mental Health System Fragmentation

State-funded mental health, substance abuse, mental retardation and developmental disability services in Missouri are offered primarily through DMH and the Division of MO HealthNet within DSS. Within DMH, three divisions serve the mental health needs of the state: the Division of Comprehensive Psychiatric Services (CPS), serving those with mental illness, ADA, providing substance abuse treatment and prevention, and the Division of Mental Retardation/Developmental Disabilities (MR/DD), assisting those with mental retardation and developmental disabilities. The Division of MO HealthNet funds services for MO HealthNet recipients in need of mental health care.

In addition to DMH and the MO HealthNet Division of DSS, several other departments and divisions also provide treatment services or contract with CPS for care. These include the Department of Corrections (DOC), the Department of Elementary and Secondary Education (DESE), two additional divisions within DSS, DHSS, the Department of Public Safety (DPS) and the Office of State Courts Administrator (OSCA).

Despite several initiatives designed to link services across departments, many initiatives and financial resources are fragmented. Departmental systems are not adequately linked to each other to provide accurate and comprehensive information regarding the mental health care provided to individual consumers. DMH provider agencies surveyed for the NARI felt strongly that further collaboration between DMH, across departments, and public/private agencies is needed, with around 75% of providers expressing either a high or critical need for collaboration in these three areas. Individual consumers and public hearing members voiced concerns about fragmentation as well. They urged better coordination between schools and mental health care providers, substance abuse and mental health care services, and primary care and mental health care professionals. Transformation work groups suggested: (1) establishing state departmental coordinating teams; (2) establishing uniform geographic services areas across divisions and departments; (3) developing common eligibility standards; (4) developing shared information systems; (5) assigning a unique consumer identifier to each consumer; (6) utilizing one coordinator across state systems for each consumer; and (7) bringing together state, local, public and private payers to develop more effective funding stream strategies.

Stakeholder Priority Needs: Workgroups, Focus Groups, Providers and Public Hearing Participants* (Needs Rank Ordered)

Stakeholder Group	Priority Needs	
Transformation Working Group members	Most Pressing Needs <ol style="list-style-type: none"> 1. Improved financing 2. Increased access to mental health care 3. Agency collaboration Critical Actions Needed <ol style="list-style-type: none"> 1. Improved financing 2. Consumer-driven care 3. Stigma reduction 	First Steps Toward System Transformation <ol style="list-style-type: none"> 1. Improved financing 2. Agency collaboration 3. Consumer-driven care 4. Stigma reduction 5. Increased access to mental health care 6. Workforce development 7. Use of evidence-based practices 8. Political buy-in
Transformation Work Group members (n=108)	Priority Needs <ol style="list-style-type: none"> 1. Increased access to mental health care 2. Improved financing 3. Agency collaboration 4. Public mental health literacy/stigma reduction 5. Consumer supports 6. Prevention/Public Health Model/Across Lifespan 7. Technology 8. Early identification 	
Focus group members	Priority Needs <ol style="list-style-type: none"> 1. Stigma reduction 2. Community involvement/outreach 2. Affordable Services 4. Specialized Providers (esp. psychiatrists) 5. Transportation 5. Increased access to mental health care 5. Prevention/Early Intervention 	<ol style="list-style-type: none"> 8. Mental/physical health integration 8. Consumer-driven care 8. Public mental health literacy 8. Ongoing recovery/support services
Mental health and substance abuse providers	Most Pressing Needs <ol style="list-style-type: none"> 1. Co-occurring disorders training/treatment 2. Affordable services 3. Better co-ordination of services 4. Community support services 5. Greater consumer choice 6. Improved financing 	Consumer Needs <ol style="list-style-type: none"> 1. Single point of entry into system 2. Transportation assistance 3. Ongoing recovery/support services 4. Provider co-occurring disorder training 5. Expanded school-based mental health services 6. Better evaluation of persons with co-occurring disorders
MR/DD providers	Needs for System Change <ol style="list-style-type: none"> 1. Improved financing 2. Better coordination/consistency of services 3. Consumer-driven care 4. Better pay for providers and staff 5. Ongoing recovery/support services 6. Psychiatric services 	Consumer Needs <ol style="list-style-type: none"> 1. Shorter waiting lists for housing 2. Affordable housing 3. Behavior management services 4. Transportation 5. Employment 6. Better paying jobs

Stakeholder Group	Priority Needs
Public Hearing Participants	<ul style="list-style-type: none"> 1. Ongoing recovery/support services 1. Agency collaboration 1. Workforce development 4. Housing 4. Revised MO HealthNet coverage/eligibility requirements 4. Specialized providers (esp. psychiatrists) 7. Transportation 8. Improved financing 8. Expand school-based mental health services 8. Co-occurring disorder services

*Duplicate numbers reflect ties.

CHAPTER THREE

NEEDS ACCORDING TO TRANSFORMATION WORKGROUPS

“We need to think outside the box”

Transformation Working Group (TWG) and Workgroup Surveys

To better assess the mental health needs of key Missouri stakeholders involved in planning, policy making, and service delivery, the Governor constituted a TWG to oversee the development of the Comprehensive Plan and to make recommendations to further inform this plan. The TWG chartered six additional workgroups to further inform the plan. The workgroups were centered on the six themes of the President’s New Freedom Commission Report.

The TWG was constituted by Missouri Governor Matt Blunt, and established through Executive Order 06-39 in April 2007. The original TWG was comprised of 18 members. This number was expanded to 24 by Executive Order 07-15. The TWG is composed of consumers, family members of consumers, key leaders from the Governor’s office, the Department of Mental Health (DMH) and other state departments/agencies (see the list at end of this chapter for more details regarding TWG composition). The TWG Leadership team has met once every quarter since January 2007 to develop and review workgroup charters, receive updates on the progress of the workgroups (culminating in the creation of the first year plan), and review and assist the Needs Assessment team.

Members of the six workgroups represented a wide range of constituencies including consumer and family members, consumer organizations, governmental agencies, mental health organizations, provider agencies, educational institutions, and corporations. The titles of each workgroup were as follows:

- *Mental Health is Essential to Overall Health*
- *Consumer and Family Driven Care*
- *Easy, Early and Equal Access to Mental Health Care*
- *Disparities Are Eliminated*
- *Evidence Based Practices*
- *Technology*

To assure effective collaboration and integration, a member of the Technology Workgroup was assigned to each workgroup. Likewise, at least one member of the evaluation team was also assigned to each group. The workgroups brought together 232 content experts from the public and private

sector. Content experts included consumer and family members, agency and program leaders, researchers and academics, providers and health care professionals. They convened in March 2007 and continued meeting through June 2007.

Procedure

The needs assessment of all groups was conducted in May 2007. A total of 108 workgroup members and 13 TWG members completed the survey. The on-line survey specifically examined participants' identification of needs to five questions:

- What are the most pressing needs that should be addressed to successfully transform mental health care in Missouri?
- What three critical actions would have the most impact on transforming mental health care in Missouri?
- What would be the first step to transforming mental health for all Missourians?
- What significant opportunities do you think we need to take advantage of in order to transform mental health for all Missourians?
- What significant barriers do you think we need to be aware of in order to transform mental health for all Missourians?

Summary of Findings (n=121)

- **Most Pressing Needs.** Improved financing and increased access to mental health care were consistently regarded as one of Missouri's most pressing needs. Also of importance were communication, collaboration and integration across both state agencies and entities external to state government.
- **Three Critical Actions.** The three most critical transforming actions were improved financing, consumer driven-care, and increased agency collaboration. Improving the public perceptions of persons with mental health needs was also ranked as an important action.
- **First steps.** First steps toward transforming the current mental health system were similar to the critical actions and included designing methods to increase easier, earlier and equal access to mental health care; improved financing; greater collaboration; educating the public on the importance of and need for transformation; and changing public perceptions of those with mental health needs versus mental illness.
- **Significant Opportunities.** Significant opportunities that TWG and work group members felt Missouri should take advantage of included: improving funding/financing opportunities and increasing programs through grants, addressing funding issues through the state's new Medicaid redesign program (MO HealthNet), having dollars follow the person, passing local tax initiatives, and using electronic data systems to streamline funding. Also of importance was taking advantage of communication and collaboration opportunities.
- **Significant Barriers.** Significant barriers to transforming the mental health system were thought to be people's perceptions of those with mental health needs versus mental illness (e.g. stigma), financing issues, resistance to system change/collaboration, and the perceived difficulties of implementing change throughout state government.

Detailed Findings

Although the TWG and work groups had similar responses to the questions (as summarized above), there were some differences in responses. This section provides detailed results from each group.

TWG Findings (n=13)

- **Most Pressing Needs.** The most pressing needs were identified as improved financing, access to care and coordination/communication across agencies.
- **Critical Actions.** The three critical actions necessary for transformation included improved financing, better agency collaboration, and consumer driven care. Developing a realistic plan and decreasing community stigma were also seen as important actions to take to transform the system.
- **First Steps towards Transformation.** TWG members listed improved financing, agency collaboration and consumer-driven care as the three most important first steps necessary to transform the mental health system. These needs were following by changing public perceptions of those with mental health needs vs. mental illness (e.g., stigma), access, workforce development, use of evidence-base practices and political buy-in.
- **Significant Opportunities.** The attention being placed on making changes to the system was seen as a definite positive opportunity among TWG members. Another often mentioned opportunity was the current work being done with the children's mental health system initiative. The system changes occurring because of 2003 legislation to develop a children's system of care in Missouri are seen as model by which to build collaboration across state and outside agencies.
- **Barriers.** Finally, financing issues and stigma were seen as barriers to achieving mental health transformation. Other barriers the need mentioning are state and federal policies that prohibit real systemic modifications in the way we do business and resistance to change among those engaged in the system.

Transformation Workgroup Findings (n=108)

- **Most Pressing Needs.** Access, improved financing, and communication/collaboration/integration were priority items. The first two of these are self-explanatory; communication/collaboration/integration, however, referred to not only those activities internal to the DMH, but also across state agencies, physical health entities, and across the lifespan. Next, frequently cited by respondents were overall system changes (n=10), education/stigma reduction/training (n=10), and consumer needs (n=7). Overall system changes engendered such specific issues as addressing the needs of youth transitioning from the children's to the adult system, evaluating consumer core needs, and increasing service capacity. The other needs cited were more easily defined. For example, the education/stigma reduction/training category included changing public perceptions of those with mental health needs vs. mental illness, reducing stigma, increasing the understanding of mental illness and training staff. Several other categories were

mentioned to a lesser degree. These included: resources (n=5); prevention/public health model/across lifespan; technology; and, early identification.

- **Critical actions.** To identify the three critical actions that would have the most transforming impact, respondents rank ordered their responses. The rankings are as follows:
 1. Improved financing
 2. Consumer-driven care
 3. Agency collaboration
 4. Improving public perceptions of those with mental health needs
 5. Easier access
 6. System changes
 7. Workforce issues
 8. Political buy-in
 9. Treatment changes

Adequate financing is clearly of concern to most persons as is consumer-driven care and interagency collaboration. Other issues such as improving public perceptions and easy, early and equal access are also of high interest.

- **First Steps toward Transformation.** First steps toward transformation generated a variety of answers. Most important first steps were easier, earlier and equal access; improved financing; greater collaboration; educating the public on the importance of and need for transformation; and changing perceptions of those with mental health needs versus mental illness. With regard to easier, earlier and equal access, the difficulties created by the large rural areas of Missouri and how they affect mental health services, were noted. Also of interest was addressing mental health at an earlier stage of illness.
- **Significant Opportunities.** The most frequently cited opportunities among work group members were financing opportunities, including the pursuit of applicable grants, addressing financial concerns through the Medicaid redesign program (MO HealthNet, exploring ways for), having dollars to “follow the person,” passing local tax initiatives, and using electronic data systems to streamline funding. Next in importance were communication and collaboration opportunities; among the suggestions made were ridding the system of duplication, developing regional collaboratives, utilizing data more effectively, and partnering with physical health. Overall system opportunities were also frequently listed with suggestions for more privatization of health services and the development of MO HealthNet. Effective use of technology by sharing data and other methods was also an important opportunity according to the work group members. Finally, changing public perceptions of mental health needs vs. mental illness, training opportunities, and taking advantage of current resources in new ways were also suggested.
- **Barriers.** Top among the barriers cited were perceptions of mental illness, finance-related issues, resistance to system change/collaboration, and the perceived difficulties of implementing change through state government. Also, the way Missourians perceive mental illness is itself a barrier--several respondents noted that even the way mental health is discussed imparts a negative connotation of illness in the public’s view. Turf issues were prominently cited under both improved financing and resistance to change/collaboration barriers. In addition, a number of

persons spoke of making sure that the executive and legislative branches of government understand and support the needs of persons with mental illness through improved financing and legislation.

Membership of the TWG includes the following:

- Chair
- Co-chair
- 2 Consumer Leaders
- 2 Family Leaders
- Senior Healthcare Policy Advisor, Office of Governor
- Director, Office of Comprehensive Child Mental Health
- State Advisory Council Chair, DMH Division of CPS
- Director, DMH Division of CPS
- Director, DMH Division of ADA
- Director, DMH Division of MR/DD
- Director, DSS Children's Division
- Director, DSS Division of Youth Services
- Director of Program Management, DSS Division of Medical Services
- Prevention Services Coordinator, DHSS
- Representative, Division of Senior & Disability Services, DHSS
- Chief of Mental Health Services, Department of Corrections
- Public Safety Manager, Department of Public Safety
- Director of ITSD-IT, DMH Office of Administration
- Assistant Commissioner, DESE Division of Vocational Rehabilitation
- Assistant Commissioner, DESE Division of Special Education
- Representative, Missouri Housing Commission
- Representative, Office of State Court Administrators

CHAPTER FOUR

SUMMARY OF NEEDS FROM DEPARTMENT OF MENTAL HEALTH-RELATED SOURCES

“Let me be part of the solution.”

Before conducting focus groups, Missouri Institute of Mental Health (MIMH) researchers reviewed recent mental health consumer reports conducted by the Department of Mental Health (DMH) and others to obtain a fully understanding of information in secondary sources related to needs and resources. The two major DMH-related studies of consumers were the “Voice of the Consumer” report that came out of focus groups conducted by the Change Innovation Agency, and “The Missouri Planning Council for Developmental Disabilities Statewide Needs Assessment,” a needs assessment of mental retardation/developmental disabilities consumers prepared by the Institute of Human Development at the University of Missouri-Kansas City (UMKC; Rinck, Graybill, Berg, & Horn, 2006). In addition, MIMH reviewed the public hearings conducted by the TWG in the summer of 2007 in order to get public input on the department’s plan. The goal of this chapter is to summarize all three of these secondary data sources in order to provide a context for the development of the focus groups, as well as provide additional perspectives regarding the needs of mental health consumers in Missouri.

“Voice of the Consumer” Focus Groups

In 2004, the DMH and the Change Innovation Agency partnered to conduct statewide focus groups to address satisfaction with the Department of Mental Health’s services. Many individuals participated in these focus groups and interviews, including consumers who access substance abuse and mental health services for themselves or others (i.e., family members), mental health providers, law enforcement, public administrators, and the deaf and hard-of-hearing. A total of 412 individuals took part in these focus groups. The feedback from this project was summarized in the “Capturing the Voice of the Consumer” report. The following information is excerpted directly from that report.

It should be noted that although MIMH gathered information and data for this needs assessment, MIMH did not collect the data for the “Capturing the Voice of the Consumer” report, nor did MIMH analyze that data. Information about this report has been taken directly from the DMH and Change and Innovation Agency report.

General Findings & Recommendations

Seven system wide recommendations, described in the document's Executive Summary, were presented. (Change and Innovation Agency, 2003).

After-care. Consumers feel that there is a lack of follow-up treatment upon completing a program or leaving in-patient care. They often do not feel prepared to move on without some kind of support (i.e., counseling, life skills training, housing assistance, job assistance, etc.).

Repeat Consumers. Consumers want services and programming that are effective, meaning that they only go through once. It seems as though DMH puts consumers through the same exact treatment although it may not have been effective the first time – there is no alternative route specialized for the repeat client.

One-on-one time with the counselor. Youth and adults alike in out-patient and in-patient care overwhelmingly wanted more time with their counselor. They want to sit down and discuss an issue without getting a prescription handed to them. Consumers also want to talk to somebody on an “as-needed” basis. Counselors that “have been in my shoes” are in high demand, as well.

Quality of Information. Consumers, especially in the Division of Alcohol and Drug Abuse (ADA), expressed concern about the age of their education material – videos, hand-outs, etc. Their major complaint was about the age and usefulness of the materials. They complained that the videos seemed like they were 15 years old, and that the materials were often things they already knew. A better way to express the content would be to provide motivational learning experiences such as trips to hospitals to see people affected by their actions, speakers, who have been in their shoes and succeeded, consumers reported.

Consumers receiving in-patient care complained about repeating the same information repeatedly, especially if they were long-term consumers. There was a real sense that they are not getting anything out of programming once they have been there for a significant length of time.

In-patient Quality of Life. Many consumers in in-patient care expressed boredom. Many focus group members wanted to do more activities, get outside for fresh air, and work out and exercise. Unfortunately, they said, many activities are cancelled or avoided due to a feeling that there aren't enough staff to allow consumers these opportunities.

Speed and Access to the System. Individuals representing referral agencies expressed strong concerns about the difficulty in getting consumers into the DMH system for anything beyond an assessment. This was particularly true for the Division of Comprehensive Psychiatric Services (CPS), where waiting lists, lack of available beds, and the inability of the Access Crisis System to carry out duties which Mental Health Coordinators used to do. They stated that response times are slow, and beds are very difficult to locate. In some cases, located beds disappear while filling out all of the paperwork that is required. The development of a Crisis Intervention team by the Lee's Summit Police Department seems to eliminate many of the complaints. Lee's Summit uses a system that was originally developed by the Memphis, Tennessee Police Department.

Staff Attitudes. Many comments centered on poor staff attitudes toward consumers. In the Methadone program, many consumers felt that staff was treating them like “criminals, not consumers” – with little respect. Many consumers in in-patient care discussed how they were held to rules that the staff don’t follow, such as prohibitions on cursing and smoking. There was a general feeling that the staff attitudes have a direct impact on consumer satisfaction or dissatisfaction.

Findings from Specific Groups

In addition to the seven system-wide recommendations presented above, findings related to specific subpopulations were also described in the Voice of the Consumer (Change Innovation Agency, 2003) report and summarized by MIMH staff for this needs assessment.

Youth in In-patient Care

Many youth in in-patient care felt that they needed better treatment from staff and greater respect. They expressed the need for more access to doctors, more appointments/visits with their doctors, and better community transition services that would improve their chances of recovery and remaining out of in-patient care. They would like to know more about their conditions and treatment.

Parents of Youth in In-patient Care

Parents expressed a desire for more accessible services and after-hour services. These parents worried that their children do not have adequate care and desired criminal prosecution for those who abuse/harm their children. Many encouraged team-oriented planning to maximize the benefit for their child. They requested that they not be isolated from their children when those children were in residential care. Parents also felt that staff should listen to them, better involve them in care decisions, and listen to their recommendations. They would like more individualized care and would like it better explained to them.

Adults in In-patient Care

Adults in in-patient care expressed the desire for more input into their treatment. They would like treatment that leads to a quicker discharge and which would better prevent relapse. Many said that they would like to become productive members of society with an ongoing system of support or after-care, including job training. They would like more access to their doctors, and requested doctors that could meet their specific needs, such as a Veterans Administration representative to meet the needs of veterans. They would like to be treated with respect and not threatened. The individuals who have been in the system over time do not like to have the same treatment constantly repeated.

Consumers Receiving Services in the Community

Consumers expressed the need for more information about their illness and treatment options; specifically related to information on anger, depression, and medications. Participants expressed a high need for independence, follow-up care, and more input in their services.

Clients Receiving Residential Care

The greatest needs of these consumers were after-care services to allow them to better transition into their communities. This included skill-building in areas such as budgeting and other practical skills. Faster access to professionals (including doctors), employment assistance, more social time, transportation and additional trips outside of the facilities were other needs expressed.

Residential Services Owners

Residential service owners participating in focus groups were very interested in improving the quality of life for residents in their facilities, and would like to be able to better meet the needs of their residents. Better communication with DMH was expressed as an important need. They would like to be notified of policy changes when they occur. There were complaints about billing and other financial issues.

Law Enforcement

Many law enforcement participants wanted a directory of services offered by DMH with contact numbers for the services. They also need facilities to provide beds in a timely manner, paperwork reduction, and additional beds. They wanted better definition of the process of commitment, including a list of reasons for a 96-hour commitment. The law enforcement participants also expressed concern that while they were dealing with the paperwork or waiting in the ER, deputies were being taken off of the road from their other work. The outcomes suggested are fast, effective treatment, minimal law enforcement contact, and long-lasting care for consumers.

Other Referral Sources Including Advocacy Organizations

CPS providers, housing/shelter providers, administrators with the Missouri Hospital Association, and members of advocacy organizations (including NAMI) were included in focus groups. Some stated that there is still a need for someone to perform the functions formerly performed by Mental Health Coordinators. They also need comprehensive services that are provided in a timely manner. Providers would like to break down the silos that fragments and isolates treatment between various departments and divisions; it takes too many steps to get to the right person. They would like individualized care and treatment and specialized services for children and promote the System of Care. According to many parents who are members of advocacy organizations, lasting results, rather than “temporary fixes” were a high priority to improve their children’s quality of life. They would also like their children to stay in their homes and work towards recovery. These parents would like the use of evidence-based programs that work, intensive services, long-term support, and they want the proper evaluation conducted at the hospital. They would like to have the family looked at as a whole. Parents would also like more inter-departmental and inter-divisional coordination.

Deaf and Hard of Hearing

Participants in these groups expressed the need for provider understanding of consumer needs, cultural exposure and sensitivity training for staff, and an assessment methodology developed for the deaf community. Many wanted mobile services to increase service access, and continued

improvement and education for physicians and professionals would work with the deaf and hard of hearing. Many felt that integrated services between DMH and the Department of Social Services (DSS) Children's Division would be helpful, as well as hiring deaf professionals and more interpreters. Education and outreach would help reduce stigma and make individuals more culturally aware. Finally, participants requested early intervention with deaf children as well as support for deaf parents of children with mental health issues.

Transformation Working Group (TWG) Public Hearings

In August and September of 2007, the TWG held public hearings across the state to get public input regarding the Missouri Mental Health Transformation initiative. TWG priorities and recommendations were presented for comment and public hearing participants verified these as priorities. A total of 421 Missourians attended the public hearings in 13 Missouri cities and towns.

Summary of Findings & Recommendations

Following the public hearings, the Transformation Planning Team posted the public response to the DMH Office of Transformation website. The report documented the main themes that arose at each location, and this section summarizes responses above and beyond participant input that was gathered for the verification of the proposed comprehensive plan.

Affordable Services

10 of 13 Sites

One of the most common themes among public hearing participants was the affordability of mental health services for consumers. The issues of MO HealthNet cuts, eligibility for services, and service restrictions were points of discussion at many public hearing sites. In addition, public hearing participants were concerned about the uninsured population, as well as the affordability of psychotropic medications.

Consumer Disparities

10 of 13 Sites

Consumer disparities in the receipt of mental health services by age, diagnosis, geographic location, ethnicity, and disability was a major concern at the majority of public hearing sites. Particular concerns included:

- Need for mental health services for the elderly;
- Issues among individuals with hearing problems, such as the lack of counselors proficient in American Sign Language (ASL), certification of interpreters, and the dearth of mental health resources specific to the population;
- Disparities in quality and access to care among consumers with autism;
- Limited services and resources in rural areas; and
- Limited services for the Hispanic population.

Workforce Issues

9 of 13 Sites

People at most sites were concerned about the lack of mental health workforce, particularly psychiatrists (7 of 13 sites mentioned a need for psychiatrists). People noted recruitment and retention of psychiatrists and/or prescribing doctors as a major concern, particularly for special populations such as children and persons with autism. Telehealth was mentioned as a possible solution to this problem at one site, whereas it was suggested that psychologists should be given prescription privileges at another. Other issues included the need for mental health workers in rural areas, a better trained and educated mental health workforce, and a need for support for mental health workers.

Prevention/Early Intervention

8 of 13 Sites

The need for prevention and early intervention was recognized at a majority of sites. Participants at six of the eight sites that mentioned prevention specifically suggested placing mental health providers in schools or linking schools with mental health services. Suicide prevention was also a need mentioned at several sites.

Consumer Housing

8 of 13 sites

Difficulties finding appropriate housing for consumers was a concern at most sites. Public hearing participants felt that mental health consumers need more positive supports to make the transition into the community. Participants also wished for an expansion of housing options and programs.

Fragmentation/Local Collaboration

8 of 13 Sites

Public hearing participants at many sites felt that local involvement is key to the success of the transformation initiative. Participants at many sites felt that collaboration among local community mental health agencies is important, particularly in rural areas where resources are limited. In addition, better communication between the state department and local agencies was also desired.

Improved Financing

6 of 13 Sites

Participants at a number of sites were concerned about financing changes that might occur with the transformation initiative. In particular, there was concern about how transformation would address duplication of services and money per agency. In addition, there were concerns about insurance reimbursement for providers and the costs of implementing evidence-based practices.

Transitional Issues

6 of 13 Sites

Speakers at sites noted difficulties transitioning consumers from one system to another (e.g., in-patient to out-patient; child to adult system; corrections to community). In particular, transitional youth (those youth transitioning from childhood to adulthood) were a concern at a number of sites. Public hearing participants felt the system should provide better continuity of services and life-cycle transition planning.

Consumer-driven Care

6 of 13 Sites

Public hearing participants at six sites suggested a number of ways to create a more consumer- and family-driven mental health system. Training for providers and consumer family members was mentioned, as was a need for consumer advocates. Public hearing participants also desired more choice in providers and less service area limitations.

Transportation

6 of 13 sites

Limited public transportation was a concern expressed at many sites. Mental health consumers need better transportation to reach appointments, go to work, and receive the education and other services necessary for a full recovery.

More Mental Health Services/Beds

6 of 13 Sites

A need for more mental health services and in-patient beds was articulated at many public hearing sites. An increase in beds and services would reduce waiting lists and help close service gaps.

Consumer/Peer Supports

6 of 13 sites

Peer support services and consumer advocates were seen as important natural community resources for individuals in mental health treatment. Additional peer support services would help consumers in recovery. In particular, participants mentioned the need for more clubhouses (so consumers can “see that they are not alone”), foster parent advocates, and more involvement with the Vet to Vet program, a recovery based program that includes peer support.

Co-occurring disorders

5 of 13 Sites

More collaborative, integrated service for individuals with co-occurring disorders, such as a co-occurring mental illness and substance use disorder, or individuals dual diagnosed with mental illness and developmental disabilities, was noted.

Evidence-Based Practices

5 of 13 Sites

At five of the 13 sites, people mentioned the need for increased implementation of evidence-based practices, although there were concerns about the cost. It was also suggested that Centers of Excellence should partner with local universities to receive research and technical assistance in the implementation of EBPs.

Consumer Employment

5 of 13 sites

The lack of employment opportunities was cited as a major barrier for mental health consumers by some participants. An increase in employment supports was desired as a partial solution.

Integration of Physical and Mental Health/Medical Services

5 of 13 Sites

Public hearing participants mentioned a number of ways in which an integration of physical and mental health care could take place. Education and support for general practitioners was recommended, as well as training for staff in emergency rooms. It was also mentioned that mental health consumers need to be provided with essential medical services and dental care.

Crisis Services

5 of 13 Sites

Public hearing participants at some sites felt that crisis services need to be improved. Increased access to local crisis beds and hotlines was recommended, as well as the increased use of Crisis Intervention Teams (CIT). Disaster preparedness was also mentioned as an important component that should be instituted at all levels of the mental health system.

Public Stigma/Education

5 of 13 Sites

Public hearing participants felt stigma was a big problem, among consumers, the public, and professional personnel. A focus on mental health promotion and a public education campaign on the first signs of mental illness were recommended.

Other Issues

People at three sites were concerned about the cost and overuse of guardianship, speakers at two sites expressed a need for better collaboration with law enforcement in dealing with mental health issues. The importance of consumer safety was mentioned at one site, as was the need for accountability measures. Finally, public hearing participants felt that the mental health system should be simplified and kept flexible in order to best meet the needs of consumers.

The Missouri Planning Council for Developmental Disabilities Statewide Needs Assessment

In 2004 and 2005, the Missouri Planning Council for Developmental Disabilities, in collaboration with the UMKC Institute of Human Development, conducted a statewide needs assessment. Individuals with disabilities and family members in each of the 11 mental retardation/developmental disabilities regions in Missouri completed a written survey (Rinck et. al., 2006). There were a total of 737 returned surveys (response rates were between 6.2% and 12.8% depending on the region) representing the responses of both persons with a disability (36.5% of written survey respondents) and family members of persons with a disability (63.5% of written survey respondents). In addition, 127 focus groups were held in 110 of 114 of Missouri's counties. There were 975 individuals who participated in the focus groups, 400 of which were disabled persons (41%) and 575 family members of disabled persons (59%). Approximately 64% of focus group participants and 70% of written survey respondents were served by the Division of Mental Retardation/Development Disabilities.

Summary of Findings & Recommendations

Both written survey respondents and focus group members were asked their opinion regarding a variety of issues relating to the needs of MR/DD consumers and their families:

- Employment Issues;
- Residential Setting Issues;
- Transportation Issues;
- Childcare Issues;
- Education/Early Intervention Issues;
- Health Care Service Issues;
- Recreational/Social Opportunity Issues;
- Community Resources/Support Issues;
- Safety and Quality Assurance; and
- Satisfaction with Services.

Employment Issues

People with disabilities were most likely to work in sheltered employment (42.2% of respondents) and least likely to have a regular job in the community. About half (55%) felt sheltered employment was good (35%) or excellent (20%), and the rest felt it was either inadequate (21%) or fair (24%). By far, the most important employment challenge for people with disabilities was finding job opportunities commensurate with their skills and abilities. Attitudes and perceptions among employers was also a big issue; respondents reported that employers had limited knowledge regarding people with disabilities, limited willingness to be flexible with disabled employees, and reluctance to hire disabled person due to fear of lawsuits.

Housing Issues

The majority of disabled persons lived with family or friends (57%), and such arrangements were seen as the most available source of housing by the majority (79%) of respondents. The biggest challenge relating to housing was the lack of accessible, affordable, safe housing in the community.

Childcare Issues

Child care was most likely to be supplied by family or friends (70%), and family care was also seen as the most adequate (by 69% of respondents). However, the number one childcare challenge for families was the lack of options for childcare in the community, followed by a lack of providers qualified to support kids with a disability and system requirements that limit childcare services.

Education/Early Intervention Issues

The most common early intervention service utilized by respondents was First Steps (42%), and the majority of respondents (61%) rated First Steps as either good or excellent. Over 73% felt that early intervention services were either mostly or somewhat available in their community.

In terms of education, the most utilized educational type was special public school education (46% of respondents), followed closely by regular public school (34%). Special public school education was seen as the most adequate educational type, with more than half (53%) of respondents regarding it as good or excellent. In terms of availability, inclusive educational opportunities were seen as either somewhat available or not available by 66% of respondents, transition services from school to work were seen as somewhat or not available by 71% of respondents, and post-high school educational services were seen as somewhat or not available by 78% of respondents. Finally, focus group respondents overwhelmingly stated that the lack of quality, individualized educational supports is the greatest challenge to maximizing student potential.

Transportation Issues

Public transportation was the most commonly used transportation among people with disabilities (47% of respondents), whereas self-transportation was least likely to be used (albeit the most desired option). By far, the number one transportation challenge for persons with disabilities is the lack of transportation availability, particularly in rural areas.

Health Care Service Issues

Respondents were most likely to use a doctor's office for health care services (reported by 62% of respondents) and least likely to use a residential health care center (3.6%) or local health department (3.6%). Interestingly, residential health care centers and local health departments received the highest ratings for adequacy (45% for residential care centers and 29% for local health departments), whereas over 67% of respondents rated doctor's offices as fair or inadequate. Hospital/emergency rooms were also considered inadequate by a majority of respondents (70%). When asked about the availability of health services for persons with disabilities, community health care services and dental services were rated as not available by 40% and 50% of respondents, respectively. Finally, respondents considered "public health insurance program (e.g., MO HealthNet) issues that impact persons with developmental disabilities" the most important health care challenge.

Recreational/Social Opportunity Issues

The number one recreational/social opportunity issue for focus group members was the lack of opportunities for recreation available in the community. The most common recreational opportunities in the community were special/segregated socializing/recreation (50%) and regular community sponsored recreation (34%). Both were rated inadequate by 60% and 72% of respondents, respectively.

Community Resources/Support Issues

The most commonly used community resource was family and friends (61%), and the least often used was civic organizations (10%; it was also seen as the most inadequate by 40% of respondents). Supports from family and friends were rated the most adequate (rated as excellent or good by 77% of respondents). Focus group members reported receiving community supports most often from family/friends and faith based organizations. The support offered by faith based organizations was rated either good or excellent by the majority of respondents (56%), whereas the majority found support from social organizations to be either inadequate or fair (60%)

Safety and Quality Assurance

Respondents were asked if they were aware of any incidents of abuse that affect the health, safety, and quality of life of individuals with disabilities. One out of every five respondents was aware of physical abuse, neglect, or financial exploitation in their community. Fully 25% were aware of human or legal rights violations, and 16% were aware of sexual abuse. About two-thirds of respondents said these violations were handled badly, or not at all. About 60% felt people with disabilities were mostly or very safe in their communities, however, 5.9% did not feel safe at all, and more than a third felt only somewhat safe.

Satisfaction with Services

Service coordination was rated good or excellent by over 70% of respondents. The quality of provider services/supports was rated good or excellent by almost 65% of respondents.

One Change to Community

Finally, respondents were asked what one change they would make in their community to make it better for persons with disabilities. Respondents wanted to enhance services for individuals with disabilities and to increase community understanding of persons with disabilities to help address attitudes and perceptions.

CHAPTER FIVE

NEEDS ACCORDING TO MENTAL HEALTH CONSUMER INTERVIEWS AND FOCUS GROUPS

Background

Mental health services and support needs often vary from community to community and group to group. Group-specific data were gathered to capture information about the unique mental health needs of specific groups which the current mental health service system may not be adequately addressing, or, in some cases, may be largely unrecognized.

During the summer of 2007, 15 focus groups (total n=191) and 23 in-person interviews with key agency informants were conducted across the state. The focus groups and interviews targeted groups often identified as being underserved or miss-served by the mental health system. Focus groups were conducted that explored how members of these groups perceived stigma, the adequacy and access to mental health information and services, quality of providers, consumer-driven care, and perceptions of the greatest mental health needs in both their local communities and across the state.

Some of the data gathered from the various groups are crosscutting, that is, multiple groups identified particular issues that were a common concern to them. These crosscutting data are presented first in a Summary of Findings and Recommendations, followed by the specific group analyses in a Detailed Focus Group and Interview Findings section.

Procedure

Prior to conducting the focus groups, the Missouri Institute of Mental Health (MIMH) staff conducted a thorough literature search to determine the extent of research that had previously been collected related to different populations of mental health consumers. This literature search indicated that additional information was needed for the following groups:

- 1) African-Americans (rural and urban)
- 2) Corrections—probation and parole
- 3) Elderly (rural and urban)
- 4) Families with children (rural and urban)
- 5) Hispanics (rural and urban)
- 6) Homeless
- 7) Lesbian, gay, bi-sexual, transgender (LGBT)
- 8) Refugees and immigrants

- 9) Rural adults
- 10) Transitional Youth

MIMH contacted agencies throughout the state to assist in the recruitment of focus group members. Focus group members received \$10 gift cards for their participation in the group. MIMH also interviewed key personnel within the agency from which focus group members were recruited, exploring stigma, information in the community related to mental health, sufficiency of mental health providers in the community, and their perceptions of the greatest needs of the population they serve.

Two researchers attended each of the focus groups, one facilitator with experience in conducting focus groups, and one recorder who also coordinated logistics. All groups were taped to assure the quality of information collected. Focus groups of African American consumers were conducted by a skilled African American facilitator. The Hispanic focus group was conducted in Spanish by a bi-lingual Hispanic with extensive experience in focus group facilitation. A mental health consumer assisted with focus group and in-person interview coordination.

Demographic Characteristics

The tables on the following pages outline details of the subgroups surveyed and demographic characteristics of focus group participants.

Focus Group Locations and Demographics

Subgroup	Location	Agency	# of Participants	Average Age	% Female
African-Americans (rural)	Caruthersville	Family Counseling Center	13	42	62%
African-Americans (urban)	Kansas City	Swope Health Services	10	46	60%
Co-occurring disorders	St. Louis	Hopewell Center	30	36	40%
Corrections--probation and parole consumers	St. Louis	State Probation and Parole	9	40	11%
Corrections--probation and parole staff	St. Louis	State Probation and Parole	11	47	73%
Elderly, rural	Bowling Green	Bowling Green Nutrition Center	8	76	88%
Elderly, rural	Chillicothe	Chillicothe Senior Center	11	81	82%
Elderly, urban	St. Louis	Five Star Senior Center	12	72	100%
Families with children	Springfield	Family Bridges	18	46	72%
Hispanics (rural) (Interviews only)	Monette	Clark Mental Health Center	NA	NA	NA
Hispanics (urban)	Kansas City	Mattie Rhodes Center	11	35	91%

Subgroup	Location	Agency	# of Participants	Average Age	% Female
Homeless	St. Louis	Community Alternatives	14	43	29%
LGBT community (interview only)	St. Louis	Southampton Healthcare Inc.	NA	NA	NA
Refugees and immigrants	St. Louis	International Institute, Islamic Center/Bosnian Cultural Center	8	NA	NA
Rural adults	Kirksville	Mark Twain Counseling Center	14	53	79%
Rural adults	St. Joe	Northwest Behavioral Health	12	45	83%
Rural adults (interview only)	Doniphan	Family Counseling Center	NA	NA	NA
Transitional youth	St. Charles	Missouri Foster Care Youth Advisory Board	10	19	70%
Total			191	49	65%

Summary of Findings and Recommendations

The sections that follow this summary detail the results of focus groups for each specific consumer group. However, taken as a whole, the focus groups also represent a large subsection of mental health consumers. When the findings from all focus groups were combined, a number of crosscutting themes spanning multiple groups emerged. Those themes are as follows (in order of most common mention):

1. Reducing Stigma/Discrimination
2. Community Involvement/Outreach
3. Affordable Services
4. Specialized Providers
5. Transportation
6. Help Finding Services
7. Prevention/Early Intervention
8. Integration of Mental and Physical Health
9. Consumer-driven Care
10. Public Mental Health Literacy
11. Meeting Basic Needs
12. Co-occurring Mental Illness/Substance Use Disorders
13. Cultural Competence

Reducing Stigma/Discrimination

Mentioned by 10 out of 10 groups

The need for a reduction in the discrimination against people with mental illness was a strong theme in every focus group. Rural respondents reported that mental illness stigma is most common among the elderly and in the workplace, and elderly respondents felt that, “there isn’t anything more demoralizing than a mental illness.” Transitional youth felt judged by other kids due to their mental illness. Persons in the families with children group reported that stigma leaves them feeling very isolated. Minorities suggested that culturally competent educational campaigns should avoid stigma-laden terms like “mental illness.”

The term “double stigma” was used by several groups, referring to the double discrimination these individuals face for both having a mental illness and being a member of a group that commonly faces discrimination. This was a strong concern among African-Americans, although they are not the only group to experience this phenomenon. For example, homeless individuals felt that people view them as “lazy bums” and thus are less motivated to help them get back on their feet or “cut them slack” for their symptoms of mental illness. A nurse interviewee, who often works with the lesbian, gay, bisexual, and/or transgender (LGBT) community, felt that the lack of legal protection against discrimination is impairing LGBT individuals’ ability to get equal treatment and access to mental health care. Finally, individuals in the corrections system reported that prisoners with mental illness are often stigmatized by prison staff, prisoners, the community, and even by their own family members.

Community Involvement/Outreach

Mentioned by 8 out of 10 groups

Focus group members felt mental health care should be integrated into communities, especially for individuals who are unable or disinclined to seek out mental health services, such as refugees and immigrants, the elderly, minorities, rural individuals, parolees, and children. For example, individuals in rural areas often must rely on other professionals (such as family doctors or pastors) for mental health treatment, so it was suggested that these professionals be better trained to deal with mental health problems and issues. Families with children believed that schools should offer more training for parents, teachers, and staff about how to work with mentally ill children. In addition, individuals in corrections felt that community-based assessment and treatment services would lead to better care for probationers and parolees.

Due to strong mental illness stigma and/or system distrust in homeless, minority, refugee/immigrant, and elderly communities, focus group members recommended providing mental health training to natural community supports such as the faith community, in-home providers, home health agencies, community centers, and transportation providers. It was suggested that training these individuals would allow them to support mental wellness, recognize risk factors, and counter social isolation.

Homeless individuals in particular reported needing more community support programs (life skills, vocational rehabilitation, job training, transportation etc.) to aid them in getting back on their feet.

Affordable Services

Mentioned by 8 out of 10 groups

Insurance was a major issue for individuals in a majority of the groups. Focus group participants, particularly those in the rural and elderly groups, pointed out that MO HealthNet (Medicaid) often has restrictions that impede the use of mental health services, such as limiting the number of doctors the insured can see in one day, or limiting the number of sessions an individual can have with a counselor. Recommendations included easing the restrictions or providing assistance with services that are not covered by MO HealthNet or Medicare. African-Americans also mentioned the need for affordable coverage for the uninsured.

Homeless persons, transitional youth, refugee/immigrants, LGBT focus group members, and prisoners/parolees mentioned difficulties finding appropriate coverage. Transitional youth often “age out” of their eligibility for children’s services with no financial means or steady employment to provide them with health insurance. Persons on probation and parole transitioning from the correctional system to society find barriers to reinstating insurance upon reentry, and LGBT individuals in committed relationships do not have the same benefits as married heterosexual couples, thus resulting in insurance gaps. The homeless often find bureaucracy gets in the way of receiving public assistance. Finally, many immigrants and refugees find it difficult to receive services given their status as non-citizens.

Specialized Providers

Mentioned by 6 out of 10 groups

Several groups mentioned the need for high quality specialists that can work effectively with their particular populations. For example, elderly focus group members mentioned the need for individuals trained in geriatric mental health care, and families with children reported needing mental health professionals who are more effective at helping their children. Additionally, there are few providers who have experience with LGBT issues or with the correctional system. Representatives from the international community reported a strong need for bilingual providers, as well as interpreters with mental health training. The need for mental health specialists, such as psychiatrists and professionals specializing in children and the elderly, is particularly strong in rural areas. It was suggested that telecommunication technologies (such as Telehealth) may give individuals in rural areas more convenient access to specialized providers located in metropolitan areas.

Transportation

Mentioned by 5 out of 10 groups

Transportation was a problem for a number of groups, particularly those in rural areas. Elderly individuals who cannot drive are in need of mobile services, and youth in rural areas reported needing transportation to drive to the closest service providers (which are often in metropolitan areas). Existing transportation services in rural areas are insufficient to meet the need, and it was suggested that Telehealth or in-home services may be ways to provide services in rural areas while alleviating the demand for transport. Transportation was a huge issue for the homeless who have difficulty getting services and gaining employment without reliable transportation. Hispanics also reported that lack of transportation makes it less likely that they will seek services.

Help Finding Services

Mentioned by 5 out of 10 groups

Difficulty finding information about available services is a barrier to services for many groups. LGBT and Hispanic group members find it difficult to know where to look for services that are most appropriate for them, and homeless focus group members wished for a “road map” of available services. Individuals in rural areas (as well as transitional youth in those areas) found it particularly difficult to find information about the services available. Many reported learning about services only through word-of-mouth.

Prevention/Early Intervention

Mentioned by 5 out of 10 groups

Several individuals in focus groups felt that prevention and early intervention are important. Rural groups, refugees/immigrants, and African-Americans reported that youth prevention programs may help prevent future mental health and substance use problems in at-risk youth. Persons with the families with children focus group believed that early intervention could save parents years of trying to diagnose their child, as well as providing help and guidance before the illness increases in severity. They felt that early intervention and screening should be offered to all youth. Finally, a better evaluation process, and an increase in drug and mental health courts, was suggested for corrections.

Integration of Mental and Physical Health

Mentioned by 4 out of 10 groups

Four out of ten groups noted that mental and physical health needs to be better integrated. This is particularly true for the elderly, where a very high proportion of seniors with mental health needs also have chronic physical illnesses that link them to the health care system. Therefore, training primary care physicians to recognize and appropriately treat geriatric mental health problems could

go a long way. The same is true for rural physicians, who are often the first point of contact for rural individuals with mental health issues and little access to mental health specialists. In addition, individuals from the families with children group pointed out that children with mental illness often have co-occurring physical illnesses, and that both should be considered in an integrated system of care. Finally,

Consumer-driven Care

Mentioned by 4 out of 10 groups

A number of individuals reported that their voices were not being heard in the current mental health system. Transitional youth felt that counselors neither listen to nor care about them, and they are forced into counseling or onto medication when they are not ready. Parents of children with mental illness believed that professionals need to do a better job of listening to parents, and that it is wrong to remove children from their homes before trying to work with families. African-Americans and homeless individuals also reported that they are often not treated with respect or included in the treatment planning process.

Public Mental Health Literacy

Mentioned by 4 out of 10 groups

Related to stigma, focus group members felt that local communities are not knowledgeable about mental illness, resulting in misperceptions of mental health treatment and increased stigma. Several individuals said that people are less likely to feel stigmatized and more likely to get help if they have more information about mental health and wellness. Transitional youth felt that mental health curricula should be placed in high schools, possibly as part of regular health classes, and the LGBT interviewee thought that diversity training would prevent the onset of mental health issues among LGBT youth. Hispanic and immigrant/refugee focus group members felt that all mental health information should be translated into the appropriate language, so that foreign-born individuals can be educated about mental illness.

Meeting Basic Needs

Mentioned by 4 out of 10 groups

The basic needs (such as affordable housing and employment) are not being met for some consumers, which makes it difficult to treat mental health difficulties. Individuals transitioning into society from the correctional system find it difficult to gain employment required as a condition of their parole. In addition to employment supports, they also find it difficult to obtain transitional housing. The homeless have similar difficulties transitioning from the streets to society—they find few services available that can help them develop the basic skills needed to become independent members of society (e.g. life skills, job training, vocational rehabilitation, stable transitional housing, etc.). Refugees and immigrants also have a difficult time adjusting to a new country and navigating the

system in order to gain employment and housing. Finally, many African-Americans felt that not having basic needs met impedes their recovery from mental illness.

Co-occurring Mental Illness/Substance Use Disorders

Mentioned by 3 out of 10 groups

The problems people experience trying to get services for both a mental illness and a substance use disorder were mentioned by three groups. Families and children felt there should be better diagnosis and treatment for adolescents with co-occurring disorders, and African-Americans believed there is a lack of services and programs for consumers with co-occurring disorders. An officer interviewed in corrections estimated that co-occurring disorders occur in “at least half” of people in the correctional system, and stated that there are not enough services to address the many needs.

Cultural Competence

Mentioned by 3 out of 10 groups

Minority groups (Hispanic, African-American) and refugee/immigrants stressed the need for cultural sensitivity for mental health professionals, as well as culturally competent education campaigns and specialists. All groups felt that involving community leaders in this process is necessary to build trust.

DETAILED FOCUS GROUP AND INTERVIEW FINDINGS

Transitional Youth

“Know me before you know my Problems.”

Summary of Findings and Recommendations:

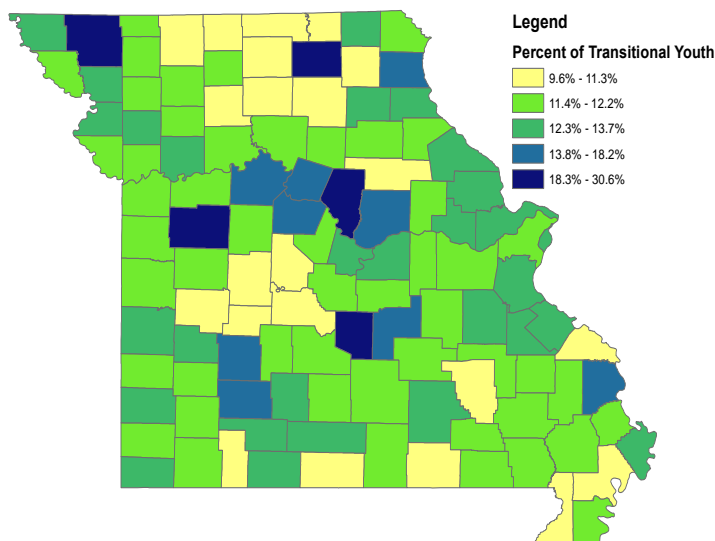
The recommendations are derived from both a focus group conducted with transitional youth in foster care and other sources referenced in this section. The youth in the focus group were members of a statewide Department of Social Services youth advisory board in Missouri.

- Many youth felt their voices were not heard in making decisions about the system and the type of care they receive. Youth wanted a voice in policy and planning development for youth with mental illness.
- There were concerns about the quality of care received. Many youth felt their counselors did not listen or care about them, and they often felt they were forced into counseling or onto medication when they were not ready. High counselor turnover exacerbates their trust issues. Both urban and rural youth were concerned about the quality of their care.
- Many youth did not feel the counselors understood their issues, and wanted to talk to someone who knew what they were going through. Youth recommended establishing a peer mentoring program similar to KUTO (Kids under Twenty-One), a suicide prevention initiative in St. Louis. This request was specific to youth in foster care.
- Insurance coverage was a major issue for the youth. Many of them aged out of children’s services at age 19 or 21, and had no access to health insurance and no financial means to pay for the expensive mental health services they needed. They recommended that supports be put in place to help these young adults continue care after leaving the child system. Cost of services is a huge problem for these youth.
- Barriers to receiving services were different for urban and rural youth. Urban youth felt there were a number of services, but found it difficult to know where to go to learn about the available services. Rural youth, on the other hand, felt that there were very few available services in their area, and that a major barrier to receiving services was finding transportation to the closest service providers (which are often in metropolitan areas).
- Youth had a number of ideas for distributing mental health information. They felt that information distributed to youth should be eye-catching and placed in areas where youth will see them, such as schools, doctor’s offices, McDonald’s, Wal-Mart, the internet, and on television. They also felt mental health curricula should be placed in high schools, possibly as part of regular health classes.

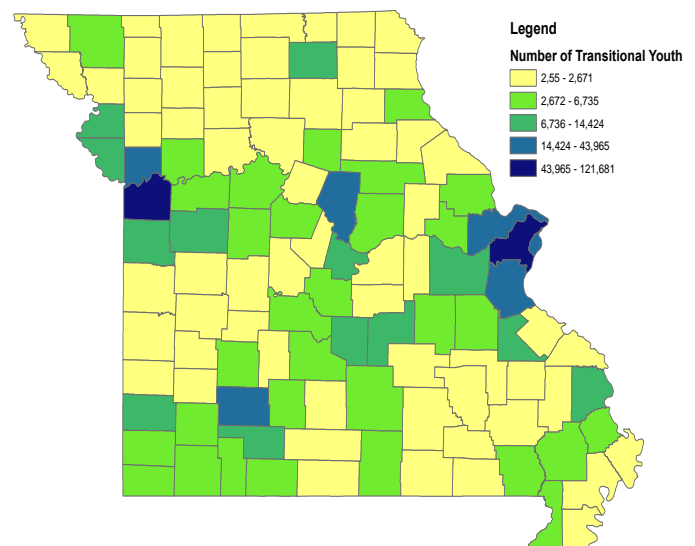
Population and Prevalence of Mental Health Difficulties among Transitional Youth

In 2005, the number of youth between the ages of 18 and 24 was 505,007, or approximately 9% of the population in Missouri. As shown in the figure below, the number of transitional youth is highest in the higher population areas, (St. Louis County and Jackson County), but the percentage of transitional youth relative to the population within each county is higher in towns with large state universities. There are relatively few transitional youth in northern and southeastern Missouri, a reflection of fewer opportunities for employment in these areas and few or no higher educational institutions.

Percent of Youth Aged 16-24 by County, 2005



Number of Youth Aged 16-24 by County, 2005



Source: 2005 U.S. Census

Note: 2005 U.S. Census data was limited to certain age ranges. Data specifically for the transitional youth age range of 16-25 was not available, so data for ages 16-24 was used instead.

According to SAMHSA, at least 6.5 million transitional youth have a psychiatric disorder (Davis & Vander Stoep, 1997). More than three million transitional youth are diagnosed with a serious mental illness (Vanderstoep, Beresford, Weiss, McKnight, Cauce & Cohen, 2000). In Missouri, approximately 21.3% of all youth between the ages of 18 and 25 suffer from severe psychiatric distress (SPD) in any given year, one of the higher rates of psychological distress in the nation (Wright, Sathe, & Spagnola, 2007). The rates of alcohol dependence and abuse (21%) and illicit drug use and abuse (8.4%) are both very high when compared to other states. Furthermore, suicide is the third leading cause of death among the ages 15-24, and less than 40 percent of at-risk youth receive services (U.S. Department of Health and Human Services, 2002; Minino, Arias, Kochanek, Murphy, & Smith, 2002). This population has critical needs but limited access to services that address these needs.

Data Sources

The findings and recommendations are derived from a focus group conducted with transitional youth and a literature review on mental health issues specific to transitional youth. The focus group was conducted in the St. Louis suburb of St. Charles, Missouri with 10 foster youth who are members of a statewide DSS youth advisory board. The youth were between the ages of 16 and 23, and the average age was 19.4 years. The group was a mixture of rural and urban youth, and 70% (n=7) were female. All but two youth were MO HealthNet recipients (the other two youth had no insurance). Six youth were Caucasian and four were African-American.

Detailed Findings: Key Themes

Voice in policy making. According to Davis (2003) and focus group youth, young people need a voice in mental health policy-making. Youth in the focus group had many ideas for improving the system. They experience the system daily, live in it, and believe that their input would help to improve their care, as well as care for other transitional youth. Throughout the focus group, these youth suggested ways to make individuals aware of mental health issues and resources and improve the quality of care in the current service system. However, they did not feel their suggestions and voices were being heard in the current system.

Quality of Services. There were mixed impressions regarding service quality. Around half of the group felt that they had received good care. Others strongly expressed the need for changes:

Listening Skills. Many youth strongly felt that the most important factor in shaping the quality of their relationship with any mental health staff (particularly counselors) was the mental health professional's ability to listen. Youth said that many of the counselors did not listen well and therefore they relied upon other people (foster parents, grandparents, friends, etc.) for support.

"We just need someone who knows how to listen."

-- Transitional youth focus group participant

Therapeutic Relationship. The youth expressed a desire to trust their counselor with their private issues, experiences and thoughts. To these youth, confidentiality is vital to a successful counseling relationship. It is extremely important that they are not seen as a number or a diagnosis, but as a person. The youth in the focus group said there should be more focus on the person instead of the diagnosis. They thought that their counselor should meet with them first, before reading their file, to prevent inaccurate preconceptions as to who the client is. They would also like a counselor to admit when the youth is not ready for counseling, and then pursue treatment at a later date so the youth is eventually treated when he or she is ready to talk and benefit from treatment. Many of these youth felt forced into counseling and treatment when they were not ready to talk about the trauma in their lives.

"If you are abused at home, they just put you on meds."

-- Transitional youth focus group participant

Continuity of Care. Turnover was a significant issue for most youth. Many had seen several counselors because of high turnover which made the youth reluctant to confide in their counselors. They suggested having an agreement between the counselor and the client which would allow both parties to know what they can expect from each other.

Changes in Medication Management. Many youth were critical of the system's tendency to medicate for mental health issues rather than provide quality individual therapy. Several said that the medications they received made them worse rather than better. They reported wanting some say in whether they are prescribed medications.

Transition from Child to Adult System. When youth age out of childhood services, including special education, child welfare system and juvenile justice systems; they are often neglected in terms of service transfer for adulthood (Davis and Vander Stoep, 1997; Davis 2003). In Missouri, this is further confounded because fewer adults qualify for mental health care through MO HealthNet than children and the SCHIP program discontinues coverage once a child reaches the age of 19. Furthermore, many young adults are no longer covered under their family insurance policy and may not yet be employed full-time (and thus not covered under an employer's policy). Therefore, it is unsurprising that young adults are most likely group to be uninsured, with 29% of women and 37% percent of men aged 21-24 uninsured in 2006 (Fronstin, 2007). This was confirmed through the focus groups. Youth stated that they were frustrated because there were no longer supports in place to obtain mental health care once they were no longer eligible to receive children's services, and treatment options are expensive. According to youth in the focus group, unless they are working and receive benefits through their employer, they have no access to insurance.

"Know me before you know my problems."

-- Transitional youth focus group participant

Peer Mentoring. The youth in the focus group recommended peer mentoring in foster care. They felt frustrated by counselors who often stated that they knew what the youth were experiencing. The youth expressed that there was no way an individual could know what they were experiencing unless they had gone through it themselves. A peer mentoring program would put them in touch with someone who has had similar experiences to the youth in foster care, which would be helpful for youth currently in the foster care system or just leaving that system. Youth who have been in foster care would be able to understand their specific issues and concerns better than counselors. The youth suggested there be more programs like the KUTO (kids under 21) peer mentoring program.

Stigma and Mental Health Information. Focus group participants felt there was significant stigma around mental health issues and expressed concern that they are judged by their illness. They

"People are afraid that what they say will be leaked and people will look at them differently, judge and act different around them."

-- Transitional youth focus group participant

had many ideas for addressing stigma and increasing knowledge related to mental illness. They emphasized the need for information with "eye appeal" (not just plain brochures) and for information to be available in places where youth would visit (doctor's office, schools, McDonalds, Wal-Mart, etc.). The internet and TV commercials were also

mentioned as good ways to reach youth. They also suggested introducing mental health curricula into high schools, possible in health classes.

Barriers to Services. Rural and urban youth had differing views on the difficulties in accessing services. Urban youth reported having a number of available services, but not always knowing where to look to find the services they need. Youth from rural areas, on the other hand, said that there were very few providers in their areas, with the exception of southeast Missouri. Like their adult counterparts, transitional youth living in rural areas reported that transportation is a barrier for them when trying to get services. For example, one youth reported driving 45 miles to get services. Transportation is even more difficult for low income youth who do not drive and who do not own an automobile.

The Elderly

“The current generation of older persons still views mental illness as a ‘personal flaw,’ not an illness that can be successfully treated.”

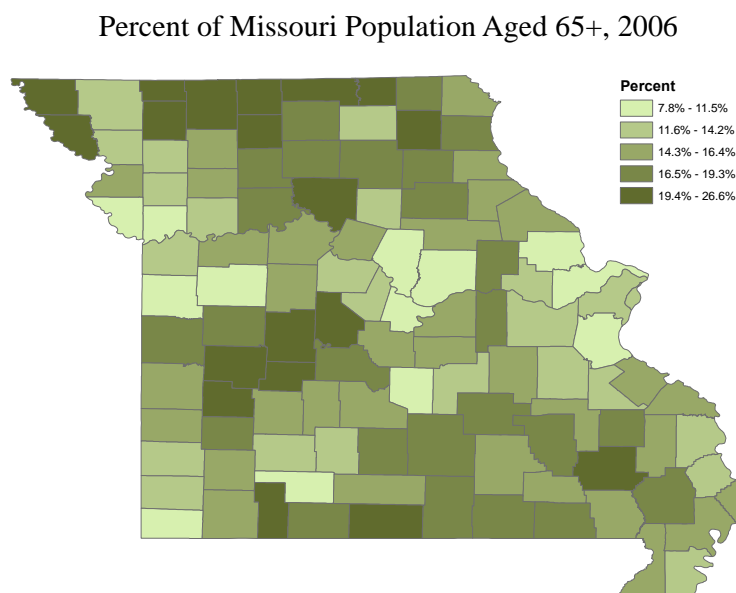
Summary of Findings and Recommendations:

The findings and recommendations in this report are derived from focus groups conducted with older adults and other sources referenced in this section.

- Provide mental health services and supports that focus on late life mental disorders that include dementia, anxiety, depression and depressive symptoms, alcohol and prescription drug abuse; emotional problems adjusting to old age (developmental changes); and persons with long-term psychiatric disabilities who are aging.
- Integrate and coordinate mental health and primary health care. A very high proportion of seniors with mental health needs also have chronic physical illnesses that link them to the health care system and the aging services system. Train primary care physicians to recognize and appropriately treat geriatric mental health problems.
- Make the portion of mental health services not covered by MO HealthNet or Medicare affordable. Make sure both consumers and providers are educated as to how to maximize available coverage.
- Engage and train natural community supports such as the faith community, in-home providers, home health agencies, senior centers, Area Agencies on Aging (AAAs), transportation providers, etc., to support mental wellness, recognize risk factors in the elderly, and counter social isolation.
- Assure appropriate access to mental health services by the elderly. Mobile services should be available in homes and in community settings, as well as increased transportation to more traditional mental health services settings.
- Provide appropriate access and development/expansion of geriatric mental health services and health and mental health professionals trained in geriatric care. This includes addiction services aimed at seniors.
- Provide more public education on aging and mental health issues including education on mental wellness, depression, stigma, and ageism.
- Study the issues raised by the need for mental health treatment in nursing facilities to craft recommendations for meeting the many unmet needs in those facilities. This could include a recommendation as to the best state home for the treatment and care of irreversible dementias in both nursing home and home-based settings.

Population and Prevalence

For purposes of this report, elderly Missourians shall be defined as persons 65 years of age or older. The choice of age 65 as the lower limit is only somewhat arbitrary.¹⁹ Based on 2006 data, there are 788,891 seniors in Missouri constituting 13.3% of the population (U.S. Census, 2006). By comparison, the elderly constitute 12.5% of the national population (U.S. Census, 2006). As can be seen in the map below, the elderly make up a large percentage of the population in several rural counties. In Missouri, the “old elderly” or persons aged 85 and over total 113,789 or 1.9% of the Missouri population (U.S. Census, 2006)]. Based on the latest available data from 2000, about 6% of elders in Missouri are institutionalized (Missouri Senior Report, 2007).



Source: U.S. Census, 2006

Determining the prevalence of mental health problems among the elderly in Missouri is problematic and varies depending on the criteria for mental health problem that are used. According to the 2005 National Survey on Drug Use and Health (NSDUH), an estimated 4.6% of older adults experience severe psychological distress (Wright, Sathe, & Spagnola, 2007). This percentage increases as people

¹⁹ Most developed nations generally accept this limit (World Health Organization, Definition of an Older or Elderly Person, <http://www.who.int/healthinfo/survey/ageingdefnolder/en/print.html>, accessed October 23, 2007). Likewise, for purposes of Medicaid waivers, the Center for Medicare and Medicaid Services (CMS) uses 65 as the lower limit for persons who are “aged” (42 CFR 441.301(b) (6)). Much population data also uses the 65 year lower limit to set age categories. However, the Older Americans Act defines the term as 60 or older (42 U.S.C.3002, Title I, Sec. 102 (40)). Given that people in developed countries have greatly expanded life expectancy and that most individuals are still in their work career at age 60, the use of 65 and over seems eminently reasonable.

age and when other factors such as chronic illness, institutionalization, isolation, and grief are present. Some mental problems, such as depression, also are associated with an increased risk for suicide. Elderly white males have the highest suicide rate of any age/gender group in the state, rising from about 30 suicides per 100,000 persons to 47 per 100,000 as white males age from 65 to 85 and over ("Mental Illness," 2007).

Data Sources

In addition to a literature review, the findings and recommendations in this report are derived from three focus groups conducted with older adults and a literature review on mental health issues specific to older adults. Two of the focus groups were in rural areas and one was in an urban area. A total of 31 individuals were in the focus groups, which were 90% female. The racial make-up of the groups was 68% Caucasian and 32% African-American. Participants were between the ages of 60 and 91 with an average age of 76 years. Almost all participants (97%) were Medicare recipients, with the exception of one individual, who did not have insurance at all. In addition to Medicare, 32% had private insurance, 29% had MO HealthNet, and 16% had some other form of insurance (such as Medigap or AARP). Only 13% of those with Medicare did not have some form of supplementary insurance.

Detailed Findings: Key Themes

Needs of Seniors in the Community

"Lots of elderly don't have anyone that cares about them."

--Elderly focus group participant

Focus group participants report that older adults commonly turn to their church when faced with emotional problems, grief, depression, or anxiety that they feel they cannot handle themselves. The church, as well as family and friends, provides the bulk of mental health supports and help many elders receive. The type of support

received from these sources can be spotty and fragmented, and varies considerably based on perceptions of normal aging, sin, and salvation. While such natural supports are vital, faith-based support cannot serve all who need help and a significant proportion of persons have mental health needs that go beyond what clergy or lay person can do.

"I would tell a friend but there are very few people I can confide in – you can't trust people. I talk to God."

-- Elderly focus group participant discussing what he would do if he had a problem with depression

The majority of older adults receiving mental health care are treated by their primary care physicians (Administration on Aging, 2001). While many primary care physicians provide excellent care, there are also many who confuse mental health problems with the debilities caused by chronic physical disease or may consider late onset mental illnesses to simply be a part of normal aging (AA, 2001). When mental health treatment is attempted by these physicians, older adults commonly receive inappropriate prescription of psychotropic medications (AA, 2001). Despite these problems, both substance abuse and mental health problems in the elderly are “highly treatable and often preventable” (Substance Abuse, and Mental Health Services Administration, 2002, p. 2). Seniors often express a desire to utilize primary care for mental health issues—it is both convenient and is provided in a setting where many older adults feel less stigmatized (Center for Mental Health Services, 2005). However, according to many focus group participants, their primary care doctors

“You have five minutes [with the doctor] unless you tell them there is something wrong. You spend \$50 - \$100 and they don’t ask.”

Elderly focus group participant

were often too busy to address their mental health needs or failed to ask them if there was anything wrong.

Furthermore, the state mental health system is neither accessed by the elderly nor does it reach out to elders. Community Mental Health Centers [CMHCs] are neither specifically trained nor funded to address the mental health problems of

older adults (CMHS, 2005). Since many of the mental health problems experienced by elderly Missourians only develop later in life, one would expect a substantial proportion of the elderly population to recent mental health services through state. However, such is not the case. In Missouri, only 294 persons aged 65 or more, out of a total for all age groups of 22,467 were served by the Division of Comprehensive Psychiatric Services (CPS) for the first time in State Fiscal Year 2006. Put otherwise, only 1.3% of first-time consumers of CPS were older adults in SFY 2006. As a point of comparison, the elderly population in Missouri constituted 13.3% of the state’s population in calendar year 2000 (U.S. Census, 2000).

In addition to mental health treatment, activities geared toward preventing depression and suicide have proven to be effective. Specifically, both support groups and peer counseling have been shown to be effective for older adults at risk for depression. Bereavement support groups, in particular, can help improve mental health status for widows and widowers (CMHS, 2005). Of course, there are many barriers hindering the utilization of mental health services by elderly Missourians. One of the most important is stigma. All three focus groups identified stigma as a major problem. Participants said that they didn’t want to “be a burden” on anyone” and that “there isn’t anything more demoralizing than a mental illness.”

“The current generation of older persons still views mental illness as a “personal flaw,” not an illness that can be successfully treated.”

-- Area Agency on Aging Director

The cost of mental health treatment is also a problem for seniors. Medicare payment for mental health treatment is less than for physical health care (Friedman and Steinhagen, 2006). While some Medicare recipients have supplemental (Medigap) insurance that may pay Medicare co-pay for

outpatient mental health treatment, many do not. Many focus group participants echoed the sentiment of one individual who said that, “affordable mental health care is the key.”

Focus group members also identified transportation as a problem. Some persons cannot access services because of lack of transportation and isolation; others are homebound or largely homebound and, physically, are unable to leave the home.

Institutional Resources and Service Needs

The number of older adults nursing facilities suffering from needs is very high. In the United been suggested that up the 88 nursing home residents suffer from health problem, including dementia with older adults who live in the incidence of depression in nursing

“...nursing homes have become the new mental institutions for older adults affected by mental health problems.”

-- Center for Mental Health report

residing in mental health States it has percent of all some mental (AA, 2001). As community, facilities is high.

It has been estimated at 12 to 22.4% for major depression, in addition to another 17 to 30% for minor depression (AA, 2001).

Nursing facilities in Canada are also places with a high incidence of mental health needs. With prevalence data for American nursing facilities hard to obtain, prevalence rates in Canadian facilities may be cited with the expectation that they are not completely unlike those in U.S. nursing facilities. In Canada, prevalence rates for mental health issues are estimated at 80 to 90%. Studies indicate that between 15 and 25% of residents in Canadian facilities suffer from major depression, while another 25% have depressive symptoms. “More the two thirds of the residents suffer from some form of dementia, 10% suffered from affective disorders and 2.4% were diagnosed as having schizophrenia or another psychiatric illness. Forty percent of the residents suffering from dementia had psychiatric complications such as depression, delusions or delirium” (Canadian Coalition for Seniors’ Mental Health, 2004, p. 14).

So common is mental illness in American nursing facilities that a recent Center for Mental Health report concluded that “. . . nursing homes have become the new mental institutions for older adults affected by mental health problems.” (CMHS, 2005, p. 7)

Mental health services available in nursing facilities are severely lacking. In the United States, most long-term nursing facility residents are funded through Medicaid. Medicaid reimbursement is made to the facility to provide for all the needs of the resident. Unfortunately, funding for mental health services has not been budgeted as a part of the reimbursement structure. Most residents do not receive the mental health care they need (AA, 2001). Although facilities must have the capacity to deliver mental health services to long-term residents funded through Medicaid, this seldom is possible.

“. . . Medicaid policies [have] discouraged nursing homes from providing specialized mental health services, and Medicaid reimbursements for nursing home patients have been too low to provide a strong incentive for participation by highly trained mental health providers. The

emphasis on community-based care, combined with inadequate nursing home reimbursement policies, has limited the development of innovative mental health services in nursing homes.” (SAMHSA, 1999, p 70)

Specific barriers to appropriate mental health assessment and treatment for residents of nursing facilities include:

- Lack of adequate MO HealthNet and Medicare reimbursement for mental health treatment;
- Lack of adequate reimbursement to secure the services of psychiatrists and other mental health professionals;
- A shortage of mental health professionals trained in geriatric mental health; Lack of nursing facility staff training and knowledge of the mental health needs of residents; (AA, 2001) and
- Lack of housing alternatives to nursing facilities (Friedman and Steinhagen, 2006). This lack can include a paucity of less restrictive environments, such as assisted living facilities, but also may be due to a lack of affordable housing and/or home and community-based service supports to make community living possible.

Individuals in Rural Communities

“It’s hard to find out where to go for help.”

Summary of Findings and Recommendations

The findings and recommendations are derived from 6 rural focus groups conducted with Caucasian, African American, and elderly adults, 6 interviews with key staff members at agencies serving these rural residents, and other sources referenced in this section.

- Focus groups elucidated several reasons why rural individuals may not access care or receive timely care, including lack of information about how to get mental health services, lack of transportation, and lack of insurance or sufficient means to pay for care, shortage of services or service providers, and mental illness stigma.
- Most focus group members said that it was difficult to find information about available services and most had learned of services through word-of-mouth. This indicates a real need for rural agencies to do more publicity and outreach.
- Although some agencies provide transportation for people in outlying regions or even provide in-home services, it is insufficient to meet the need. A solution might be to provide outreach transportation and in-home services in rural areas, as well as making greater use of telecommunication technologies (e.g. Telehealth).
- Access to services in rural areas is also impeded by lack of mental health specialists and few choices for mental health care. An increase in the use of Telehealth technologies may be a way to help alleviate these problems.
- Substance abuse services and in-patient and crisis beds were particularly strong needs of rural focus group members. Focus group participants reported traveling long distances to reach AA meetings and hospitals that provide substance abuse services or crisis care.
- Less access to mental health professionals means that rural individuals often rely on other professionals, such as family physicians or clergy, for their mental health needs. Therefore, it is recommended that these professionals are trained to confront mental health issues.
- Approximately 23% of the rural population are MO HealthNet recipients. Focus groups suggested easing MO HealthNet restrictions to make it easier to get mental health services.
- Mental illness stigma was an issue for some, but not all, focus group members. However, most focus group members felt mental illness stigma was a larger issue among the elderly and in the workplace. They felt that early intervention was key, as was public education about mental illness.

Population and Prevalence of Mental Health Difficulties in Rural Areas

According to the 2000 census, 103 counties, or 89% of Missouri's counties, are considered rural, i.e., not containing urbanized areas (Missouri Office of Rural Health Biennial Report 2004-2005). The prevalence of mental illness in general is virtually the same for rural and urban areas with the exception of youth's alcohol use, adult stimulant use, depression in women and suicide rates which are higher in rural areas (Van Gundy, K. 2006).

In a survey of over 1000 residents of northeast Missouri, 31.9% of the respondents listed "depression" as the most important unmet service need (Northeast Missouri Regional Health Assessment Project, 2005). Suicide was the second leading cause of death for rural (national) 24-35 year olds and the fourth leading cause for this age group as a whole. Even though rates are not available for 40 Missouri rural counties, 100% of the counties in which suicides are greater than the state rate are rural (Missouri Office of Rural Health Biennial Report 2004-2005).

However, problems of accessibility, acceptability and availability cause many rural consumers to enter into treatment at a later stage than urban consumers, by which time their symptoms are more persistent, serious and disabling, requiring more expensive and intensive care. Accessibility of services is a barrier in rural areas because of the distances between residents and services, the limited number of emergency and regular services, difficulties recruiting and keeping mental health service providers, and inadequate transportation. Services tend to be located in the larger towns and cities within an area with some satellite offices spread throughout the region. Although some agencies provide transportation for people in outlying regions or even provide in-home services, it is insufficient to meet the need. In a study of health care utilization, it was found that individuals with their own transportation made significantly more health care visits than did people who had to rely upon public transportation or other forms of transportation (Arcury, Preisser, Gesler, and Powers, 2005).

Data Sources

The findings and recommendations are derived from six focus groups conducted with two groups of rural elderly adults, two groups of white rural adults, one group of African-American rural adults, six interviews with service providers in rural areas, and a literature review on mental health issues specific to rural individuals. The focus groups were conducted throughout the state with 57 adults recruited by local mental health agencies and senior centers. The participants were between the ages of 24 and 91, and the average age was 58 years. Seventy-eight percent were females; 6% had no health insurance; 38% were MO HealthNet recipients; 55% were on Medicare; 31% had private insurance; and 11% indicated that they had "other" insurance. Many participants endorsed having more than one insurance source. Approximately 66% were Caucasian, 28% were African-American, 2% were Native American, and 5% were "Other." There were no Hispanics or Asians in the groups.

Detailed Findings: Key Themes

Information about Services. Most focus group members said that it was difficult to find information about available services and most had learned of services through word-of-mouth. This indicates a real need for agencies to do more publicity and outreach. Members of the clergy were mentioned frequently both as sources of information and as supports. Since so many individuals rely upon clergy for support and referral, it is important to provide them with general mental health information as well as referral information.

“It is hard to find out where to go for help.”

-- Rural focus group participant

Interviews with staff at senior centers revealed that they did not have referral information readily available and that their focus was primarily on the physical status of the seniors. The seniors themselves denied having any mental health problems—just grief when a friend passes away, yet it is estimated that as many as a quarter of seniors have mental health needs. Lack of information about culturally appropriate services was also a concern for rural ethnic minorities.

Transportation. Lack of transportation and the need to travel long distances were specifically mentioned as significant barriers to accessing care. Some agencies provide transportation and there was mention of limited access to rural buses, but the need for these methods of transportation to make multiple stops to pick up passengers increases the amount of time spent accessing services. Additionally, these modes of transportation are limited in number and availability.

“You can only access transportation Monday-Friday; what if you have an emergency over the weekend?”

-- Rural focus group participant

Insurance and MO HealthNet (Medicaid). Lack of insurance coverage is a major barrier to service according to focus group members and staff interviewed. Insurance is often tied to employment, so high unemployment in rural areas impacts insurance availability. Furthermore, small businesses located in rural areas often do not offer insurance benefits. In rural areas, 22.7% of the population are MO HealthNet recipients, compared to 10.7% of the urban population (State Profiles of Medicaid and SCHIP in Rural and Urban Areas, 2007). Little more than 12% (12.3%) of Missourians lack health care insurance. In the 11-county rural area of the northeast, 18.42% lack insurance (Northeast Missouri Regional Health Assessment Project, 2005). In the referenced Northeast Missouri survey, 56.3% of respondents said that insurance was unaffordable, 44% said that prescription drugs were unaffordable, and 36.9% did not know whether mental health care was affordable.

Restrictions that are a part of MO HealthNet also impact access. For example, one restriction allows only one visit to a mental health provider on any given day, so people have to make two visits to see both a therapist and a psychiatrist. Focus group members stated that many medications were unaffordable. MO HealthNet reimbursements for psychiatric services are also very low, according to staff.

Lack of Choice. Agencies are located in the largest towns in the region, sometimes with satellite offices in smaller towns, but there are still many people who are geographically isolated. Focus group members stated that there is a lack of choice of services because there are so few services available. In one focus group, most participants had reportedly received poor care from their original mental health provider, but found good care at an agency addressing both physical and mental health care needs. This is a choice that is not available in most communities where there is a single service provider in remote parts of the state.

Shortage of specialists. The need for mental health specialists is great. In fact, 37% of state and local rural health leaders responding to a survey selected mental health and mental disorders as one of their top rural health priorities, after access, oral health, and diabetes (Gamm, Hutchison, Bellamy, et al., 2002). Nationally, among 1,253 smaller rural counties with populations of 2,500 to 20,000, nearly three-fourths of these rural counties lack a psychiatrist, and 95% lack a child psychiatrist (Holzer, Goldsmith, and Ciarlo, 1998). At all focus groups, the shortage of psychiatrists was mentioned, particularly for children and seniors. There are only 85 geriatric psychiatrists in all of Missouri and child psychiatrists are clustered in the urban areas.

Due to the shortage of specialists, primary care physicians are the principal mental health providers in many rural areas. Nationally, 60% of the rural population lives in areas of shortage of professionals (both mental and physical health) and 65% receive mental health treatment from primary care physicians (Gale & Lambert 2006). According to researchers, many rural physicians may intentionally under-diagnose mental illness due to doubts about the patient's acceptance of a mental disorder diagnosis, stigma, or a concern about the patient's future insurability (Gamm, Stone and Pittman 2003). According to a national study, rural doctors detected depression 50% less than physicians in urban areas (Mental Health and Rural America: 1994-2005, 2006).

Members from one focus group discussed the lack of continuity of care that results from a shortage of psychiatrists and resultant reliance on primary care physicians. Since a local rural agency contracts with four different part-time psychiatrists, focus group members stated that they rarely know which doctor will treat them when they make an appointment. Although the psychiatrist prescribes the medication, they see their primary care physician for follow-up and continued care and usually the physician has little understanding of their diagnosis or the effects and side-effects of their medications. This situation points out the need for more intensive mental health training and continuing education for general practitioners in rural areas, as well as more psychiatrists in rural areas or access to Telehealth services.

Telehealth. Telehealth has shown promise as a means to provide services to individuals in medically underserved areas and allow consumers in those areas more service options. In northeast Missouri, a telehealth system is under construction. Presently it serves individuals from 11 sites with planned expansion of services. Of 965 uses to date, 90% have been for mental health. Research shows a high level of consumer satisfaction with telehealth services (Hilty, Nesbitt, Kuenneth, Cruz, and Hales, 2007; O'Reilly, Bishop, Maddox, Hutchinson, Fisman, and Takhar, 2007). Telehealth may offer individuals in rural areas easier access to mental health specialists and more treatment options, and remove transportation as a barrier to receiving services.

Inpatient and Crisis Care. People in rural areas have to travel to larger towns or cities to access inpatient care. Hospitals find it too expensive to maintain units for children and youth, so children are often transported long distances if there is need for hospitalization (Redfedder, 2005). In Missouri, extra beds have been added to hospitals in St. Louis to accommodate young people from rural areas in southeast Missouri.

In some areas law enforcement is called upon to transport suicidal individuals to hospitals, and they don't always know in advance whether the hospital will accept the patient. The distance from the hospital also makes it difficult for family members to visit or participate in treatment conferences. In one of the focus groups we learned that the community had a bed in one of the agencies reserved for crisis situations, but some individuals stated that they were denied access for reasons unknown. There are Access Crisis Intervention (ACI) hotlines available for crisis situations and the numbers are publicized through public service announcements (PSAs) and brochures in doctor's offices. Most people in the focus groups, with the exception of elderly focus group members, were aware of these hotlines.

Availability of Substance Abuse Treatment. Care for substance abuse in rural areas is limited and focus group members were particularly concerned about adolescents needing care. There is, an enormous difference in the availability of treatment with 26.5% of urban hospitals offering substance abuse as compared to 10.7% of rural hospitals. Additionally, the federal government provides greater funding for treatment to urban areas (Hutchison and Blakely, 2003). Alcoholics Anonymous (AA) is a source of support, but often people have to travel considerable distances to get to a meeting. Additionally, adult stimulant abuse is prevalent in rural areas and there are few, if any, Narcotics Anonymous groups in rural areas.

Stigma. When asked about stigma, there were varying opinions. Some focus group members believed that there were more social supports available in rural areas, while others said they would not even reveal their mental health conditions to close friends. Some members believed that stigma was lessening, but others disagreed. It was agreed that stigma in the workplace was a significant problem. Among the elderly in particular, stigma often prevents seniors from attempting to access services. A strong rural ethic dictates that people should solve their own problems. Focus group members agreed that more mental health education was needed in all sectors of society in order to reduce stigma and increase identification of individuals needing treatment, and particularly that it should begin at an early age.

"They got rid of a pastor who admitted to being depressed."

-- Rural focus group participant

African-Americans

“No matter what the situation, you have a right to your own opinion.”

Summary of Findings and Recommendations

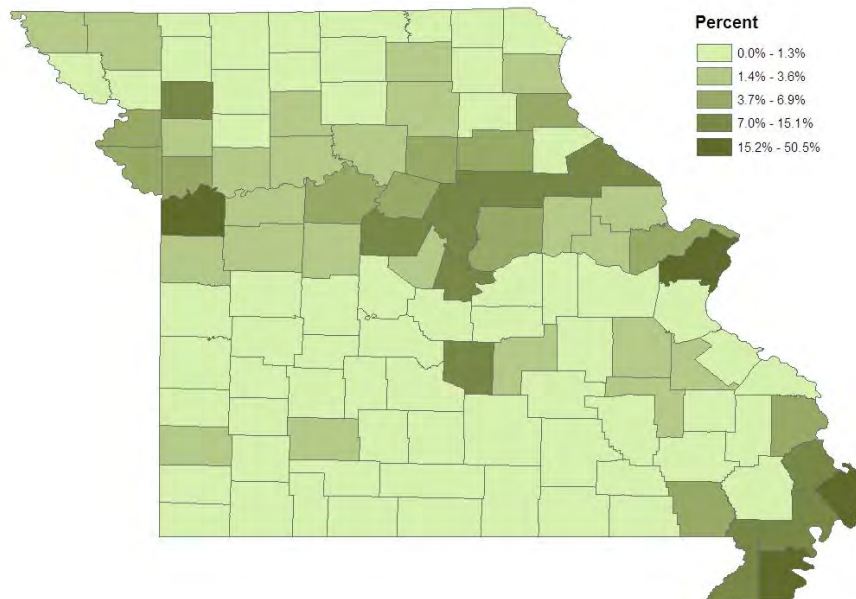
The following findings and recommendations were derived from two focus groups with African-American consumers, two in-person interviews with staff at agencies who serve the African-American population, and other sources cited in the report.

- Conduct public awareness campaigns to educate and reduce the shame and stigma of mental health issues. Involve community leaders in anti-stigma campaigns and outreach initiatives to eliminate mental health disparities among the African-American community.
- Develop public education campaigns that target stigma and discrimination and are which are tailored to the needs and culture of the African-American community. Many individuals felt doubly stigmatized by their mental illness and by being an African-American. Provide intensive cultural competence programs for mental health professionals.
- Provide youth prevention programs particularly in the rural areas may help prevent future mental health and substance use problems in African-American youth. Provide more recreational and enrichment activities for youth.
- Increase the number of mental health professionals (psychologists, psychiatrists, social workers, therapists, case workers) and providers. Match consumers and mental health professionals appropriately, reduce caseworker turnover, and train health care professionals to both treat consumers with respect and to include consumers in the treatment process.
- Train mental health professionals around medication management and delivery. In addition, train providers to incorporate consumers in the medication administration and delivery process.
- Educate the community as to the scope of available mental health services. Create drop-in centers for consumers, particularly during the evening and weekend hours. Conduct outreach to the faith community as a means to educate African-Americans about mental illness.
- Meet basic needs (i.e., healthcare, transportation, and housing) and reduce waiting lists and wait times for consumers.
- Increase services and programs for consumers with co-occurring disorders.

Population and Prevalence of Mental Health Difficulties among African-Americans

Next to Caucasians, the largest racial/ethnic group in Missouri is African-American (11.2%) (U.S. Census Bureau, 2006). As can be seen on the map below, a large majority of African-Americans reside in either in St. Louis, Kansas City, or along the Interstate 70 corridor, with almost a third living in St. Louis County (U.S. Census Bureau, 2006). In addition, African-Americans make up a large percentage of the population in the southeast region, known as the Bootheel. Overall, the African-American population in Missouri is growing at a faster rate than the White population (4.2% vs. 2.3% rate of growth between 2000 and 2004) (Office of Social and Economic Data Analysis, 2007).

Percent of Missouri Population that is African-American, by County, 2006



Source: U.S. Census Bureau, Population Estimates, 2006

According to the Behavioral Risk Factor Surveillance System, 13% of the African-American population reported having eight or more mentally unhealthy days out of the past thirty, a rate similar to Caucasians. However, there are significant differences across the state, with almost 30% of African-Americans in the northeast and southwest reporting eight or more mentally unhealthy days out of the last 30 days. (Missouri Information for Community Assessment, 2007)

Furthermore, national data show that African-Americans generally have less access to care than Caucasians, receive poorer care, and have longer wait times to receive services (Wells, 2001). In Missouri, African-Americans tend to use emergency rooms to access mental health care. In 2005, the Missouri African-American population utilized the emergency room for mental disorders at a higher rate (approximately 15 visits per 1,000), than both the White (10 visits per 1,000) and Hispanic (3 visits per 1,000) population. The rate of visits is particularly high for African-Americans aged 25-44 (approximately 24 visits per 1,000).

Data Sources

The data from this section were derived from two focus groups with African-American consumers conducted by the MIMH, two in-person interviews with staff at agencies who serve the African-American population and other sources cited in the report. The two focus groups conducted by the MIMH included a total of 23 African-Americans living in either Kansas City or Caruthersville, MO. The group was 60% female and the average age of participants was 44. Approximately 70% of the participants were MO HealthNet recipients, 18% Medicare, 4% had private insurance and 4% had medical coverage (4% missing).

Detailed Findings: Key Themes

Stigma in the African-American Community. As with other racial/ethnic groups, focus group members in urban and rural areas felt there was a significant amount of stigma associated with mental illness in their community, though they felt they could turn to their families for support. They mentioned that the community does not understand persons with mental illness--they are perceived as being "less worthy" or that they "did something" to bring this upon themselves. Other focus group members mentioned not only stigma from the general public but stigma from the service system. Focus group members and Gary (2005) reported that, as a result of being stigmatized, they felt shame which contributed to an unwillingness to seek help. Therefore, it is recommended that public awareness and understanding be enhanced in an effort to reduce the shame and stigma of mental health issues. Another recommendation is to better involve community leaders in anti-stigma campaigns and outreach efforts.

"I've had people try to run me down and beat me up...the basic person is going to say he's got mental problems; he is crazy."

-- African-American focus group participant

Double Stigma. Focus group members felt a "double stigma" due to being both mentally ill and African-American. Some of the focus groups members, particularly in the rural communities, expressed feelings of discrimination. Several mentioned that the "black" side of town is littered with unsafe parks, liquor stores, and junk yards while the "white" side of town has clean neighborhoods with sidewalks and safe parks. They also wanted to know why the "government" comes to their neighborhoods around elections, but at no other times. They indicated that there are very few health care professionals that represent the African-American community--actually there is very little diversity at all among health care professionals. This was also mentioned by the African-American key informant (from the urban community), who stressed the need for more culturally competent providers. Rural focus group members also mentioned that cultural competency as a big issue. This

“double stigma” is one reason why African-Americans may decide not to seek or adequately participate in mental health treatment (Gary, 2005). It is felt that public education campaigns targeting stigma and discrimination that are tailored to the needs and culture of the African-American community, and efforts to increase the diversity and cultural competency of mental health professionals will help. However, problems will still remain as a concomitant to the basic structure of racism and discrimination in Missouri.

“I am telling you there is nothing for young folks to do...”

-- African-American focus group participant

Youth Programs. Focus group members, particularly in the rural communities, mentioned that there is not enough for young people to do in their community. They recommended establishing youth programs because many youth are becoming involved in several risk-taking behaviors. They reported that many

youth may end up using alcohol and drugs because they have nothing to do all day except sit at home and watch television--they have nowhere to socialize. The parks are not safe and there is no movie theater or skating rink. There are also not many jobs available. They also mentioned that the neighborhoods are often littered with liquor stores and car lots. Focus group members in a rural community stated, “The church is the only place to go but they don’t have activities for the youth.” Therefore, it is recommended that more recreational and enrichment activities be available for youth, particularly in the rural communities. Focus group members in an urban community also mentioned providing classes and/or education to youth who have a parent with a mental illness to help them better understand their parent’s circumstance.

Mental Health Professionals. Focus group members and key informants in both urban and rural communities mentioned that individuals felt that there is a real lack of providers and mental health professionals available in their communities. Focus group members also said that the mismatch of counselors, therapists, and case workers makes it difficult for consumers to trust and work well with some of these professionals. As was seen with other groups (e.g., transitional youth and refugee/immigrant consumers), there is a sentiment that appropriate matching of consumers and counselors encourages consumers to enter and stay in treatment. Focus group members also stressed the difficulties that they have with the high turnover of case managers. They felt like they are being

“Sometimes it’s...borderline abusive, not physically or anything. They want you to think their way like they’re trying to mold little children but [we are] adults, no matter what the situation, you have a right to your own opinion.”

-- African-American focus group participant

“I know from people that [primary care physicians] prescribe medication for people and they are totally like a zombie, out of their heads. You need to go to a psychiatrist or a therapist, somebody who’s trained to give you this mediation.”

-- African-American focus group participant

“bounced around” from one caseworker to another, which makes it difficult to connect with their caseworker. They indicated that a lot of the caseworkers quit because they felt overloaded.

Focus group members in both urban and rural areas also commented that they are treated like “children,” that the mental

health care professionals are not including them in their treatment, and are making all the decisions for them. A culture of consumer-participation in the treatment process and the adoption of a consumer-driven services system is recommended.

Medication Administration. Some focus group members felt primary care physicians prescribed medications without the full understanding of their mental health needs and that they would rather be referred directly to a mental health professional for medication. Training for primary care physicians around medication management and delivery is recommended. Focus group members also felt like they were not sufficiently involved in medication issues—particularly as to the type of medication and the number of different medications.

Community Outreach. Focus group members and the key informant from the rural community mentioned that people do not know what services are available in their community. They suggested educating the community about mental health services by having a rally or barbeque and providing pamphlets on mental illness, in addition to creating media campaigns on the radio and television to help inform the public. Focus group members from urban areas indicated that they know about the services in the community but they want access to more services in the evening and on weekends. They mentioned creating drop-in centers where people can come together to socialize, participate in activities (e.g., arts and crafts, games, etc.), and take care of their hygiene (i.e., take a shower, change clothes, use restroom). Another suggestion made by the key informant was to hire a public relations person that understands mental health, alcohol/drug addiction, and has a working relationship with the community mental health agencies. This individual would work in the community to educate individuals, schools, businesses, etc., about services available to mental health consumers. Research indicates that African-Americans may turn to informal sources of care such as pastors, friends, and family (Neighbors & Jackson, 1984). Pastors often play the role of counselor, diagnostician, or referral agent for African-Americans (Levin, 1986). Therefore, outreach to pastors as a means to educate African-Americans about mental illness is recommended critical need.

Housing, Transportation, and Health Care Coverage. Key informants and focus group members, particularly in urban areas, mentioned that there is very little affordable and safe housing. In addition, almost all focus group members in both urban and rural areas felt that transportation is a significant issue. They reported that transportation by van or bus is often unreliable because of inconvenient running times, schedule conflicts, and inaccessible routes (e.g., rural locations). In addition, almost all focus group members and both key informants mentioned making health care and affordable medicine available to uninsured individuals. Focus group members also experienced long waiting lists and wait times to access services.

“If people were aware of [services] maybe there would be more people [accessing services].”

-- African-American focus group participant

Co-occurring Services. Most focus group members and key informants indicated that there is need for more services for consumers with co-occurring disorders.

Hispanic Community

“We live in isolation that [may] make us more susceptible to depression.”

Summary of Findings and Recommendations

The findings and recommendations in this section were derived from a focus group with Hispanic Missourians, interviews with key informants from a mental health agency serving Hispanics in southwest Missouri, as well as secondary sources.

- Wide distribution of mental health information within Hispanic communities is wanted in order to educate Latinos about mental health issues and provide referrals. It was suggested that these materials steer away from stigmatizing language linking mental health with severe mental illness.
- There is a demand for Spanish translations of mental health related materials (brochures, PSAs, etc.). Hispanic-serving agency staff and focus group participants felt that the Hispanic population would become better informed about mental illness and seek needed help if materials were translated.
- Research on cultural competence and focus groups stressed the need for cultural sensitivity training for mental health providers, including better education about the Hispanic culture. Cultural sensitivity needs to be considered in the development of mental health materials as well.
- Non-mental health providers, including the faith community, physical health providers, and schools, were perceived to be important to providing mental health care outreach to the Hispanic population. Specifically, through education of these natural providers, members of the Hispanic community could better understand mental illness and accept assistance when needed.
- Additional mental health service providers within Hispanic communities are needed. Currently, communities have very few Latino providers. Language and transportation barriers make many Hispanics less likely to seek services.

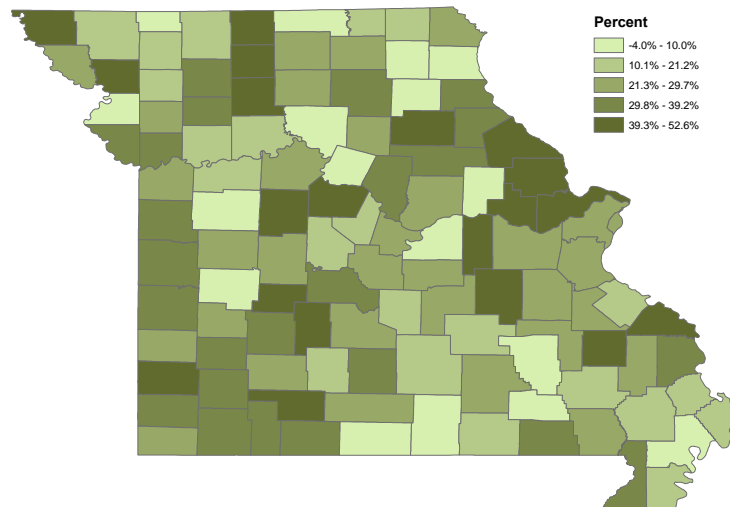
Population and Prevalence of Mental Health Difficulties among Hispanics

Hispanics in Missouri represent a diverse mix of cultural groups, including those who identify themselves as Mexican, Mexican-American, Chicano, Puerto Rican, Cuban or those who indicate origins in Spain, Spanish speaking countries of Central or South America, or the Dominican Republic (Missouri Foundation for Health, 2005). At present, around 3% of the population in Missouri is Hispanic, but this is increasing rapidly. While the total population for Missouri increased by 2.8% between 2000 and 2004, the Hispanic population, according to population projections, shows a 24.9%

increase (Missouri State Data Center, 2005). The largest population increases were among young adults (20- to 24-year-old males had the single largest increase) and young children under five.

While the greatest number of Hispanics live in the St. Louis and Kansas City areas, many rural areas, particularly in southwest Missouri, have a significant Latino population, many of whom were recruited to work in meat and poultry processing plants (Missouri Foundation for Health, 2005).

Missouri Hispanic Population Growth, 2000-2006



Source: U.S. Census, 2000-2006

It estimated that approximately 11.7% of Hispanics age 18 and older experience frequent serious psychological distress (SPD) in any given year, slightly higher than the prevalence rate for non-Hispanic Caucasians (NSDUH, 2006). Hispanic public middle and high school students in Missouri reported higher rates of suicide ideation (17%) than non-Hispanic youth (14%) (Missouri Student Survey, 2006). In a national study of mental health disparities, Hispanics were less likely to be receiving active alcoholism, drug abuse or mental health treatment than non-Hispanics, in part because they are less likely to pursue getting help. Fewer than one out of eleven individuals contact mental health specialists and even fewer (one out of five) contact health care providers (NOPCAS, 2003). When Hispanics do obtain services, their mental health care is insufficient (Hough, et al., 1987) and they are more likely to have delayed care than Whites (Wells et al. 2001).

Data Sources

The information in this section is derived from a focus group held at the Mattie Rhodes Center in Kansas City, Missouri, from interviews with mental health staff at the Clark Center in Monett, Missouri, and from a literature review. In the focus group held in Kansas City, there were 11 Spanish-speaking focus group participants, most of whom were women and an average age of 35.

The focus group was conducted in Spanish by a mental health professional and has been transcribed into English.

Detailed Findings: Key Themes

Public Information and Stigma. In general, there is stigma attached to mental illness in this community (NOPCAS, 2003). Focus group findings and interviews with service providers support this finding. Many individuals stated that within the Hispanic community, the stigma against mental illness is strong and inhibits people with needs from seeking help from mental health care providers. Those with mental health issues are still regarded as “crazy” and are socially ostracized, and issues are either discussed only within the family or by their family physician. Education of the community regarding the benefits of seeking help was encouraged. It was suggested that even the terms “mental health” and “mental illness” promote negative stereotypes of persons with mental illness, and it was suggested that other terminology be used in all informational materials (U.S. Department of Health and Human Services, 1999; focus group participants, agency interviews).

Language Barriers. In the year 2000, about 42% of Hispanics reported that they did not speak English very well (U.S. Census, 2000). Particularly in Missouri, because the Hispanic community is very small compared to the White and African-American community, resources have limited providing mental health services in Spanish, as well as the translation of mental health materials into Spanish. In the survey of mental health agencies in Missouri conducted for this needs assessment (see Chapters 6 & 7), only 11.7% of agencies/organizations surveyed reported serving the Hispanic/Latino population compared to the 93.3% that served Whites. The result is that most Missouri Hispanics have limited access to information about mental illness and to ethnically or linguistically similar providers. There is therefore a strong need both for translated materials and for training Hispanics to become mental health professionals to better serve this population.

“Use simple language...remember that there are many Hispanics here who have hardly finished elementary school.”

-- Hispanic focus group participant

Cultural Sensitivity Training. Because the number of Hispanics is very small compared to the number of Caucasians and African-Americans in Missouri, focus group members and agency personnel felt that there is a lack of understanding of the Hispanic culture among service providers. Some focus group members cited racial discrimination as an issue among mental health providers. Elsewhere, training in cultural sensitivity for health care providers working with Hispanics has been encouraged (Moran, 2004).

Training of Non-mental Health Providers.

Mental health training of faith-based organizations, schools, and physical health providers has been shown to be a good place to start in introducing concepts of mental health (Chalfant, 1990). Many Hispanics trust their pastors and feel more comfortable approaching them than they feel approaching mental health agencies. In part, there is a general fear of government among many Hispanics due to INS concerns.

“We thought that a therapist only treated crazy people. Now we have learned that a therapist is just somebody that can help us to deal with the problems we are suffering.”

-- Hispanic focus group participant

Language barriers between Spanish-speaking Hispanics and most mental health agencies also prevent many Hispanics from seeking services (agency interviews). In addition, schools provide a natural training ground for Hispanic children to learn about mental health issues. Finally, Hispanics tend to talk to their physicians about any mental health care issues that they may have. Establishing collaborative relations between primary care providers and mental health care specialists can increase accessibility to mental health care and improve consumers' mental health status (Wells, Sherbourne et al., 2000). By training non-mental health providers (pastors, teachers, physicians, etc.), the understanding of mental health issues may increase within the general Latino community. One resource for the faith community is the Pathways to Promise, a national, interfaith technical assistance organization that focuses upon mental health issues for pastors (pathways2promise.org).

Additional Providers within the Hispanic Community. Because of the reticence of many Hispanics to seek services outside of their community, a need for mental health providers within their communities was expressed in interviews and focus groups and supported in mental health research. Focus group members stated that there are language barriers, transportation issues, and issues related to cultural sensitivity that discourage them from seeking help, and that there are a limited number of providers within the Hispanic communities. Training of Hispanics to enter the mental health field was encouraged (agency interviews).

“Most of us have suffered the experience of going to big hospitals and we have to wait a lot or we have to go accompanied by somebody who speaks English if we want to be helped faster.”

-- Hispanic focus group participant

Families with Children

“The current system traumatizes kids and parents.”

Summary of Findings and Recommendations

The recommendations presented are derived from a focus group that was held in southwest Missouri. The participants were family members of children with mental and physical health problems. Some of the recommendations come from an interview with the executive director of a family organization in the area.

- There are not many resources for families with children, particularly in rural areas. Families need more diversity in both providers and services options in their area.
- Sometimes families fear having law enforcement involved with their children’s issues, because law enforcement does not always know how to handle the problem correctly. There should be more training for law enforcement on handling situations involving people with mental health issues.
- Parents have the most contact with their children and in many cases can thoroughly describe their child’s illness. Training of professionals to carefully listen to parents to further their understanding of the child’s health issues would help with diagnosis and treatment.
- The parents in the focus group expressed great concern that the crisis services in their areas are inadequate to meet their needs.
- The school systems do not always know how to handle situations involving children with mental illness. Better mental health training for teachers might help improve their understanding of the symptoms of mental illness and how to get help.
- Participants in the focus group felt that children are often removed from their homes before the situation is assessed and a plan is developed. The system should try to work with families before youth are removed from their homes.
- Many parents do not understand the symptoms of mental illness. Early screening and assessment could save these parents many years in trying to find a diagnosis for their child, and early intervention could provide help and guidance before the situation increases in severity.
- Many children suffer from both a physical illness and a mental illness, or a substance abuse issue. There should be better diagnosis and treatment for youth with co-occurring disorders.
- Stigma can leave families feeling very isolated. An anti-stigma campaign may help to improve public perceptions of persons with mental illness.

Population and Prevalence of Mental Health Difficulties among Children

As described in Chapter One, an estimated 5-9% of children nationally suffer from serious emotional disturbance (SED). According to the National Survey of Children’s Health (NSCH, 2003), 8.7% of children and youth (ages 4 – 17) (93,629 children) in Missouri have moderate or severe difficulties in

the areas of emotions, concentration, behavior, or the ability to get along with others, and 5.4% (54,115) suffer from severe SED.

Data Sources

One focus group of 18 families members with children were included as part of the needs assessment. Participants in this focus group were ages 18 to 79 with a mean age of 46.2. They were from a family organization located in a rural area in southwest Missouri. The group was mostly female and primarily Caucasian. The type of insurance that these individuals had was split almost evenly between private insurance, MO HealthNet, and self-pay.

Detailed Findings: Key Themes

Lack of Choices in Providers and Services.

Parents would like more options when trying to obtain services. Parents felt that the lack of choices in their community makes it difficult to find appropriate care for their children. In addition, they stated that there is a high turnover rate among workers in this field, hence parents are constantly starting over with new providers and caseworkers. The southwest portion of Missouri is mostly rural, with the exception of Springfield. With many services only available in urban areas, these parents have to travel a considerable distance to access services.

"Even if you know where to go for help, there are just long waiting lists...there is not access to services right away."

-- Parent from Families with Children focus group

Parents in this group also expressed frustration because their children sometimes receive different diagnoses from different providers. One woman stated it took eleven years for her child to be diagnosed with autism.

There is also a problem accessing only the services that a child needs. For example, parents have to access the "whole pie," instead of just the resources that their child needs. They felt that better individualized care could benefit both the child and the system costs.

The focus group participants had major concerns about crisis services in their area. Some participants had stories of great difficulty in accessing services regarding their crisis situations they had faced. Resources are insufficient and unsatisfactory when there is an emergency.

"Not everyone has a case manager and not every case manager has a crisis plan."

-- Parent from Families with Children focus group

School and Law Enforcement. According to the focus group participants, law enforcement needs better training on handling youth with mental and/or physical health issues. One woman explained that law enforcement is called to the school if a child has a

"melt-down," regardless of the age of the child. Many of the parents in this group stated that they home school their children because they do not want their children to have negative experiences with the police. There is a general consensus that, while trying to keep people safe, Law enforcement often uses unnecessary force when dealing with SED youth. This can cause youth to fear law enforcement.

Parents believed that crisis planning is weak and employees in the juvenile justice system need to be better trained.

Parents were also concerned that many requirements stemming from the No Child Left Behind Act of 2001 (Public Law 107-110) are not having the intended effect of helping children succeed. Finally, there are often issues with medication in the schools; sometimes schools will not permit certain medication to be provided.

"You're an expert on your own kid."

-- Parent from Families with Children focus group

Lack of High Quality Staff. The parents in this focus group were extremely knowledgeable about youth and mental health issues. They deal with these issues every day. One parent, who is a mental health worker, stated that she felt like she spent most of the meeting time with her counselor

having to educate the counselor, rather than the counselor helping her to understand her child. While she felt there was no productive reason to continue to see this counselor, the need for a good counselor is still there. Some of the parents explained that their children have had five or more caseworkers, and they have to start over each time they have a new caseworker. Also, these parents stated that sometimes parents just need a break, and help would be greatly appreciated. Caseworkers are young and not well-trained. They often have far less experience than the parents, yet they have the right to take children out of the home. These parents feel that it is difficult to understand these issues unless it is actually experienced in one's home.

Backwards System. Parents felt that the current system is "backwards." Too often children are removed from the home as a first step, instead of a last resort. The parents in this group would prefer help being offered before the child has to leave the home. The current system traumatizes both the child and the family. It would be best if the parents could work with the children in the home, instead of having them immediately removed. Litigation is expensive when the courts become involved in these cases. Parents know their children and feel they can participate in their care. Hoagwood, Horowitz, Stiffman, Weisz, et. Al (2000) found that parents are accurate reporters of their children's mental health service use. Parents can be relied on to give accurate reports of mental health service use in in-patient, out-patient, or school settings.

Early Intervention. The parents also recommended early intervention and screening for youth. They urged that physicians use a screening tool at their regular doctor's visits. According to this group, primary health care doctors do not talk with mental health providers, and vice versa. It is the parents' job to go back-and-forth to relay messages between providers. This is not only inefficient, but, at times, it results in "disconnects" that have tragic consequences.

"It took me thirteen years to find the right person...it took them eleven years to diagnose my child."

-- Parent from Families with Children focus group

Parents stated that it is extremely difficult to diagnosis children with co-occurring Serious Emotional Disorders and mental retardation/developmental disabilities, for example, a child who is both autistic and bi-polar. It is difficult to serve these children as well. Better training and earlier intervention can help these children and their families.

Stigma. Many of these parents felt that people, even those working in the field, do not understand their children and their mental health problems. Neither do people in the community understand. People in the community are often so uncomfortable around such children that some parents feel forced to keep their children at home most of the time. One parent explained that she does not want her community to know about her children's problems, and take measures to make sure it is kept quiet. She moved out to the country, home schools, and gets their medication from out of town.

According to the parents in this group, other children ridicule their children and this makes it difficult. One woman told a personal story about an acquaintance whose daughter had an accident that resulted in a mental/physical disability. She stated that this woman expressed to her how she used to be one of those people who judged and she really did not understand the personal difficulties of the situation until she was forced to deal with it every day with her own daughter.

Corrections—Prison, Probation and Parole

“They have 30 days of meds and after that they don’t have any meds.”

Summary of Findings and Recommendations

The findings and recommendations are derived from a focus group conducted with adults on probation and parole, a literature review, interviews with probation and parole officers, and an interview with the Chief of Mental Health Services at the Missouri Department of Corrections (DOC).

- Consider increasing the number of drug courts and mental health courts to divert individuals from the prisons.
- Evaluate the process for diagnosing, monitoring and treating the mental health needs of prisoners to assure that the mental health needs of all offenders are met.
- Increase the number and qualifications of psychiatrists serving the prison population. The number of psychiatrists treating the prison population is very low.
- Provide mental health education, both within the correctional system and in the community at large, to overcome the double-stigma that mentally ill offenders face.
- Carefully evaluate the need to use punitive practices in prison that may exacerbate mental health issues and limit access to therapeutic offerings.
- Assure that released offenders have adequate medications to meet their needs during reentry.
- Take steps to speed up the evaluation process for probationers and parolees by providing more community-based assessment/treatment services, increasing the number and qualifications of psychiatrists, and monitoring compliance of agreements with mental health care agencies to assure that no one is denied services due to lack of insurance.
- Provide resources for full implementation of the Transition Accountability Plan (TAP).
- Suspend rather than terminate MO HealthNet and Medicare coverage when individuals enter the correctional system. Require that applications for MO HealthNet and Social Security Disability (SSD) be made during the transitional phase from prison.
- Provide more services for co-occurring disorders and increase case management.
- Assure greater access to low-cost/free medications.
- Provide more subsidized transitional housing, transportation options, access to vocational rehabilitation, and employment supports.

Establish linkages with dentists and physicians to assure that physical health needs are met.

Population and Prevalence of Mental Health Difficulties among Corrections Population

In 2006, Missouri ranked seventh in the U.S. in the rate of overall incarceration, with 30,859 offenders in the Missouri correctional population. Incarceration rates are highest in Lafayette and Saline Counties, the Bootheel region, and in the City of St. Louis where poverty and unemployment are also high (Missouri Department of Corrections, 2006). Most offenders were white, male, and between 20-39 years old. African-Americans have higher rates of incarceration than Caucasians, (1,979 per 100,000 compared to

370 per 100,000). Female offenders accounted for 8.4% of the prison population. Drug manufacturing, sale, and possession offenses equaled about 20% of all offenses in 2006. Over half (59.5%) of offenders have a high school diploma/GED or higher, while 12.8% of offenders attain only 0-2nd grade educations at assessment (MO DOC, 2006). One study reports that over half of the prison population is functionally illiterate (Schniro, 2000).

At the end of 2005 there were 71,673 active probation and parole cases in Missouri. Missouri ranked seventh in the U.S. for the number of persons under community supervision with a rate of 414 per 100,000 population (U.S. Department of Justice, November 2006).

Mental Health. Out of 30,141 offenders in the Missouri Department of Corrections (MO DOC) assessed in 2006, only 14.8% were diagnosed as requiring treatment, and 33.8% were considered as having “minimal impairment” (MO DOC, 2006). Nationally, 56% of state prisoners were diagnosed with a mental illness (U.S. Department of Justice, September 2006). It should be noted that a significantly higher percentage of females are classified as needing services than males. In Missouri, offenders with mental illness are 4% more likely to return to prison within two years of release than other offenders. A 2006 U.S. Bureau of Justice Statistics report stated that almost a quarter of offenders in jails and state prisons who suffered from mental illness had three or more prior sentences (News Release, 2007).

Substance Abuse. In Missouri, 77% of offenders were identified as in need of substance abuse treatment upon admission, although this is most likely an underestimate as almost one-sixth of the population was not evaluated. DOC estimates that 55% of offenders need substance abuse education and 20% need treatment. The success rate of offenders completing institutional substance abuse treatment was over 75% and the rate for completing community-based rehabilitation programs was around 50% (MO DOC, 2006).

Behavioral health services for the Missouri correctional system are contracted to Mental Health Management which in turn subcontracts psychiatric services. Additionally, the DOC staff work closely with the Department of Mental Health (DMH) to provide in-patient mental health treatment. DMH provides a total of 242 beds for psychiatric treatment, over 850 beds for drug/alcohol treatment, and 60 beds to serve offenders with mental retardation and developmental disabilities to prepare them for return to the general prison population (Offender Behavioral Health Services, n.d.).

Data Sources

The findings and recommendations are derived from a focus group conducted with adults on probation and parole, and probation and parole staff. Interviews with two probation and parole staff and the Chief of Mental Health Services at the Missouri Department of Corrections (DOC). The focus group of probationers and parolees was conducted in the St. Louis City, with nine individuals who were recruited by probation and parole officers. Participants were between the ages of 22 and 59, with an average age of 40 years. Eight were males and one was female. Thirty-eight of the participants had no health insurance, and the rest (63%) were MO HealthNet recipients. Twenty-two percent were Caucasian and 78% were African-American.

Detailed Findings: Key Themes

Increase Diversion Programs. Adult and Juvenile Drug Courts and Mental Health Courts have been set up to divert offenders with chronic alcohol/drug addictions or mental illness from the correctional setting (Your Missouri Courts, n.d.). The recidivism rate for drug court graduates is about 5% compared to about 45% for those not in drug court (22nd Judicial Court of Missouri, n.d.). Currently, there are approximately 3,000 individuals under Drug Court supervision in 108 Drug Courts throughout Missouri. The program is driven by funding. There are a full range of services provided through the Drug Courts, including treatment, housing and job assistance and educational assistance. By contrast, there are only five counties with Mental Health Courts, and they are not able to provide housing, job assistance, or educational assistance due to lack of funding. They serve approximately 150 individuals.

Need for Education. The need to better educate prison staff, prisoners, and community and family members was mentioned by focus group participants, particularly in relation to the double-stigma that they felt. Many individuals stated that even their own family members stigmatized them because they don't understand mental illness. One parole officer said, "It's really almost ignorance to even call what they experience 'stigma,' because it's not a high enough level to even be stigma. It's just complete utter ignorance, and very much mystical or supernatural." Parole officers stated that most parolees do not receive an explanation of their diagnoses or of the potential effects or side-effects of their medications. This failure to involve them negatively affects medication compliance.

Diagnostics and Monitoring. Many focus group members were concerned about the quality of psychiatry staff willing to serve those in prison. Parole officers reported that when a prisoner is released, only a "face sheet" with a diagnosis is available to them. They feel that the mental illness is often misdiagnosed. "I don't think they get evaluations. They get whatever meds they have available because what they get out on the private sector is different from the institution." Prison diagnostic procedures include an immediate screen upon entry to identify seriously mentally ill individuals in order to send them to appropriate institutions and a full diagnostic evaluation within 48 hours of incarceration. Those with more severe ratings (3-5) receive more intensive care. In prison, individuals are given up to a 90-day supply of medication and are seen periodically (about every three months) by a psychiatrist. There are therapeutic programs offered, but not therapy.

Prison Practices. Some focus group members found the conditions in the prison made it difficult for them to sleep or function. One individual, diagnosed with depression while incarcerated, stated he was no longer depressed after release. Parole officers indicated that is not uncommon.

Medication and Evaluation. All offenders with a Mental Health 3, 4 or 5 level of diagnosis are mandated to have an evaluation completed as a condition of parole. Upon release from prison, they are given a 30-day supply of medication, but it often takes 30 to 60 days to get an evaluation and then another 30 to 60 days to see a psychiatrist and obtain a prescription “if they get to the appointments.” This gap in medication increases the likelihood that both physical and mental functioning can be impaired without gradual tapering down on psychotropic medications. The likelihood of self-medication with street drugs increases, as does recidivism and the possibility of self-injury. The problem is

“So you hope for them to get so sick or suicidal or you hope that they commit a minor crime...”

-- Parole officer, explaining what is necessary for parolees to receive help

confounded because some providers will not take individuals without insurance. From a parole officer: “So you hope for them to get so sick or suicidal, or you hope that they commit a minor crime. It’s pathetic to be put in that position—when that’s what we’re waiting for, and hoping that that happens, so that we can get them help. That’s the reality of it.” Speeding up the evaluation process was stated as a top priority by the officers. “If we

just had, by region, an LCSW or MSW that could diagnose and make referrals, or where we could call a number instead of having to patch together their treatment here. . .” The parole officers strongly expressed the need to have on staff or direct access to a mental health professional to do evaluations and referrals for the parolees.

Transitional Services. The need for transitional services from prison to community was expressed by focus group members. Ninety-seven percent (97%) of all Missouri offenders are returned back to their communities necessitating careful planning for successful reentry. In 2006, almost a third of the prison population (11,334 offenders) and over half of all admissions were made up of returnees to prison from parole for either technical or legal violations showing a high rate of recidivism (Transition Accountability Plan, n.d.). In response to this situation, the governor directed the Corrections Department to formulate an effective re-entry plan (Missouri Reentry Process, 2006). The DOC has begun to implement a 5 phase Transitional Accountability Plan (TAP), beginning with the initial diagnostic screening and continuing through release from prison and completion of parole (Transition Accountability Plan, n.d.). TAP, through the cooperative efforts of numerous state agencies, will assist with housing, medical appointments, employment and provision of a state ID card prior to release from prison. It is now in the initial phase of implementation.

MO HealthNet (Medicaid). According to both focus group members and parole officers, it takes a long time to be approved for MO HealthNet. Several focus group members said that they had to use lawyers in order to obtain standing and to be placed on Social Security Disability, in part, they said, because the correctional system will not release medical records. Some service providers will not see an uninsured individual, so MO HealthNet approval is essential. Parole officers reported that some states have agreements to suspend Medicaid for qualified individuals rather than terminating it. This would speed reinstatement. Applications for both MO HealthNet and Social Security Disability (SSD) should be completed in prison prior to release to assist the transition.

Treatment. More services for co-occurring disorders are needed. Many offenders need services for both substance abuse issues and a co-occurring mental illness. One officer stated that “at least half of the people [have] co-occurring [mental illness and substance abuse difficulties].” Probation and parole officers also believed that access to individual therapy is needed. According to the literature, the most effective treatment for any mental illness is a combination of drugs and therapy. However, focus group members stated that they had a difficult time affording medications, even when available at reduced cost or for just for an insurance co-pay. Probation and parole officers stated that more case management is needed because many of the individuals on their caseloads cannot manage the affairs of daily living. They do not remember to take medications, their personal hygiene is poor, and they have difficulty getting to scheduled appointments: “They don’t even know what day it is.”

“At least half of the people [have] co-occurring [mental illness and substance abuse difficulties].”

-- Probation/parole officer

Basic Needs. Reentry into society requires that individuals obtain stable housing and employment, if they are capable of handling a job. These are conditions of probation and parole, yet unemployment of persons reentering society is greater than the general unemployment in the state. That the majority of institutionalized individuals lack education and skills needed to gain employment, adds to the problem. DOC has limited training opportunities available for offenders who are serving long-term sentences, providing GED programs for both probationers and institutionalized offenders. Until offenders with mental health issues are stable, however, these programs have limited success. None of the focus group members had been able to access vocational rehabilitation services, and probation and parole officers stated that few qualified. In addition, focus group members stated they cannot afford decent housing, especially upon release and before they obtain employment or Social Security Disability, yet stable housing is a requirement of probation and parole. Transportation both in urban and rural areas is a problem for these individuals. Several of the focus group members stated that lack of access to telephones made it difficult for them to find housing, employment or to contact their probation/parole officers. People with mental illness often have more physical illnesses than the general population, so access to general medical care is also a basic need. Officers mentioned that people who abused drugs, particularly meth, desperately needed access to dentistry.

Training for Probation and Parole Officers. Although some of the larger municipalities have probation and parole officers who are designated for offenders with mental health needs, most areas do not have specialized officers. Previous training in mental health is not a requirement for designation as a mental health probation/parole officer, but most have some background. Most probation and parole officers have clients with mental illness on their caseload and in our interview, most believed they could benefit from more training.

Refugee and Immigrants

“People come [to seek services] but very infrequently because there is so much shame to speak of these problems”

Summary of Findings and Recommendations:

The following recommendations are based on a focus group conducted with Bosnian refugees and five interviews conducted with staff members from a local agency that works with the refugee and immigrant population in the St. Louis area.

- Due to the stigma and cultural barriers to receiving mental health treatment, integration of mental health services into the refugee and immigrant community is vital.
- Culturally competent educational campaigns that incorporate community leaders and avoid stigma-laden terms like “mental illness” were suggested.
- Providing youth prevention programs specific to refugee and immigrant youth may help prevent future mental health and substance use problems in this at-risk population.
- It is important to increase the number of professionals trained to work with the international community, potentially by increasing the number of training courses and providing incentives for refugees and immigrants to go into the mental health field.
- There is a need to train interpreters about confidentiality, mental health issues, and trauma and torture. It is also important to ensure that the interpreter and the client are a good fit.
- Many immigrants and refugees are victims of mass violence and persecution. It is important that mental health professionals working within those communities understand the impact of those types of traumatic experiences on the individual and the community.
- It was suggested that work be done to meet basic needs of arriving refugees and immigrants (i.e., health care, public assistance, and housing), as well as providing additional MO HealthNet coverage for therapy services, to account for the extra therapeutic challenges in treating this population.

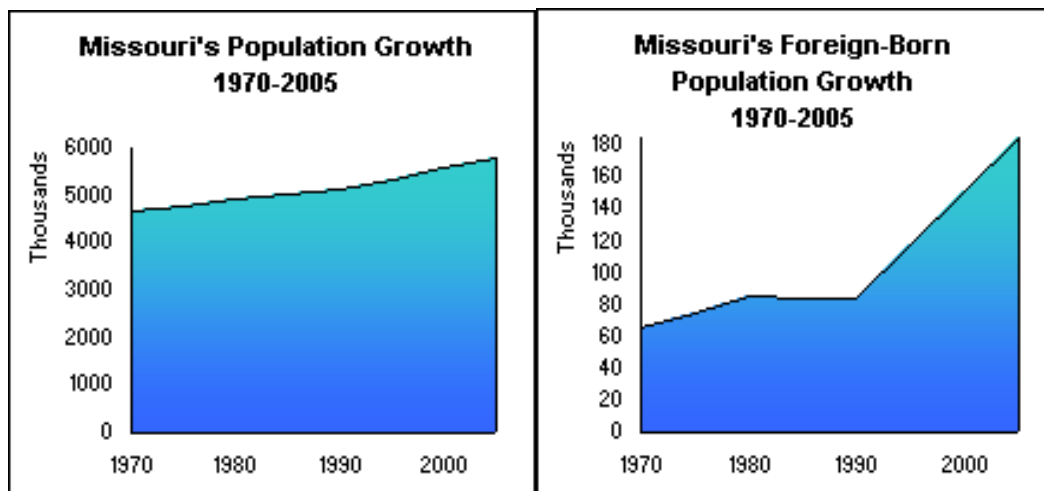
Population and Prevalence of Mental Health Difficulties among Immigrants and Refugees

Missouri’s population has been slowly increasing over the years. However, the foreign-born population in Missouri has been increasing at a dramatically rapid pace. Between 2000 and 2006 the foreign-born population in Missouri increased by 28.6% (FAIR, 2006).

As the refugee and immigrant population grows, so do their needs. When considering those needs it is important to know that refugees and immigrants have sometimes endured significant hardships in their homeland (i.e., poverty, war trauma, persecution, terrorism, natural disasters, and famine). These stressors often have a painful effect on individuals’ mental health and ability to successfully acculturate into their new communities. Not only are pre-migration and migration stressors difficult for this population, but post-migration stressors (e.g., language barriers, unsafe and unaffordable housing, poverty, job security, discrimination, and prejudice) also have an adverse affect on refugees’ and immigrants’ mental health (Pumariega, Rothe, & Pumariego, 2005). According to Keyes (2000) these

traumas and stressors that refugees and immigrants have experienced put them at high risk for mental health problems. It has been reported that many refugee and immigrant adults suffer from depression, anxiety disorders, and post-traumatic stress disorder (PTSD) (Mollica, et al., 2001; Maddern, 2004). A study conducted by Fazel & Stein in 2003 reported that over one quarter of refugee children were found to have psychological disturbances. Another study conducted with Cambodian refugees found that 86% of the Cambodians interviewed met the DSM-IV-R criteria for PTSD. Substance misuse may be another risk factor for refugees and immigrants. However, there is very little systematic data available about the types of substances and the patterns of use among refugees and immigrants (D'Avanzo, 1997).

Missouri's Total and Foreign Born Population Growth 1970-2005



Source: FAIR 2006

Data Sources

The findings and recommendations are derived from a focus group conducted with eight adult Bosnian refugees, five key informants, and a literature review. The key informant interviews were conducted with staff members from an agency that works with the refugee and immigrant population in the St. Louis area. Information gathered from a literature review on mental health issues specific to refugees and immigrants was also incorporated into the recommendations. The demographic information for six of the eight focus group participants included one female and five males, ages ranged from 37-53, all were married, and their incomes ranged from \$25,000 to over \$70,000.

Detailed Findings: Key Themes

Community-based Mental Health Services. Key informants recommended taking a community-based approach to providing mental health services to refugee and immigrant populations. They stated that the mainstream mental health system has a hard time meeting the needs due to lack of resources, language barriers, cultural differences, and stigma. It was suggested that creating more refugee and

immigrant oriented services within the community and partnering with agencies to train staff to be cultural competent would better serve this vulnerable population. The community-wide approach also includes, but is not limited to, mental health services based in schools (Fazel & Stein, 2002), community agencies, and prevention programs (Palinkas et al., 2003), and programs to teach immigrants and refugees about cultural norms in the U.S. (Pumariega, Rothe, & Pumariego, 2005). According to Pumariega, Winters, & Huffine (2003) the integration of community mental health services and the natural environment of refugees and immigrants are vital when addressing the mental health needs of refugee and immigrant children, adults, and their families. The focus group members mentioned that they would all “feel better” if the Bosnian community was able to build a planned cultural center where individuals could come and socialize with each other – a place for common sharing.

Stigma. Key informants suggested the language “mental health” be changed to something less stigmatizing so the refugee and immigrant population feels more comfortable accessing services. The majority of the refugee and immigrant cultures view individuals with a mental illness as being “crazy” and if you have a mental illness you are either “put in an insane asylum, locked in the back room of the family’s home” or left out on the street (personal communication, July 5, 2007). It was also mentioned that alcoholism is a major problem in immigrant and refugee communities, but that many individuals will not seek treatment because they see their alcoholism as normative behavior. Therefore, it is recommended that public information campaigns be conducted to educate and reduce the stigma of mental health issues. It was also recommended to involve community leaders in an anti-stigma campaign and outreach to break down cultural barriers.

“A child is not a weed that grows by itself.”

-- Staff member at an agency that serves immigrants and refugees

Youth Programs. Key informants recommended establishing youth prevention programs because refugee and immigrant youth are becoming involved in several risk-taking behaviors. They reported that many youth (particularly males) have been using alcohol, drugs, and driving recklessly. In addition, key informants and Pumariega, Rothe, & Pumariego (2005) explain that many refugee and immigrant youth go

through an identity crisis when they arrive in the United States. The youth are often unsure of which culture to identify with, which may lead to them feeling alienated from their families and their mainstream peers. In addition, many male youth lack male role models because their fathers, uncles, brothers, etc. have been killed in the war, and as a result they experience difficulties reconciling cultural differences in gender roles. Providing youth prevention programs will help to ensure youth have positive role models and may aid in youth development, self-confidence, and community building.

Mental Health Professionals. Focus group members and all key informants suggested there be an increase in the number of caseworkers, therapists, psychiatrist, psychologists, and primary care physicians that are trained in identifying and treating mental illness and trained to work with the international community (Walker, 2005). Pumariega, Rothe, & Pumariego (2005) also recommended that mental health professionals be knowledgeable of the circumstances of the refugee’s crisis and that they speak the same language or have competent interpreters available to interpret. Key informants suggested offering incentives to refugees and immigrants to work as mental health professionals within the international communities. They indicated that refugees and immigrants typically are very uncomfortable discussing mental health issues and they would be more comfortable talking about their problems to mental health professionals who were from their homeland and spoke the same language. Therefore, it was recommended that individuals within refugee and immigrant communities be

empowered, encouraged, and provided incentives to seek employment in the mental health field. In addition, they recommended that providers be educated about the traditional cultures of their refugee and immigrant consumers, and that social work and psychology students be required to take more courses geared toward the refugee and immigrant populations.

Interpreters. Several recommendations from focus group members and key informants were made in regards to training interpreters. For example, they felt there was a need to train interpreters around confidentiality, mental health issues, war, trauma, torture, and cultural competency. They mentioned that many interpreters do not understand or support mental health, which has made it difficult for the interpreters to interact well with the therapists and/or consumers during sessions. In addition, it was reported that many interpreters do not understand the U.S. concept of client confidentiality, which may be problematic because the interpreter and the client often live within the same community. Therefore, consumers have been hesitant to confide in therapists because interpreters may let other people in the community know about their mental health status. Another suggestion made by a key informant was to screen all interpreters to ensure that all interpreters have a mental health background and that the interpreter and client are the correct “fit”. For example, although Muslim and Serb Bosnians both speak the same language it would be detrimental to have Serb interpreting for a Muslim, and vice versa, due to historical tensions between the two ethnic groups.

“Interpreters are the bridge between therapists and clients.”

-- Staff member at an agency that serves immigrants and refugees

Victims of Trauma and Violence. Also mentioned was the need for more supportive services to assist victims of human rights violations and mass violence. It was explained that the “single” trauma (e.g., rape, murder, etc) that Americans experienced are very different than the traumas (e.g., war, persecution, mass violence) refugees and immigrants have experienced. These traumas often affect and dismantle entire communities. Therefore, mental health agencies and professionals need to be better equipped to address mass violence and human rights violations among refugees and immigrants.

Housing and Health Care Coverage. Key informants made several recommendations based on basic needs for refugees and immigrants. They report that public housing in Missouri has been closed which creates a big barrier for new arrivals, so it is recommended that there be an increase in the supply of safe and affordable housing for refugees and immigrants. They also mentioned making health care and affordable medicine available to uninsured individuals. In addition, key informants suggested increasing the number of therapy sessions allotted under MO HealthNet, since it often takes time for consumers to “feel safe” with their therapists and that many mental health issues do not appear until long after the individual has arrived in the U.S. They also suggested increasing the amount that MO HealthNet reimburses for therapy services, so more refugee and immigrants can receive services.

Homeless Community

“Tough love doesn’t work...I’ve had tough love my whole life.”

Summary of Findings and Recommendations

The findings and recommendations are derived from both a focus group conducted with homeless adults, an interview with a key staff member at an agency that serves the homeless, and other sources referenced in this section.

- Homeless focus group members wished for a “road map” of available services. Homeless individuals found they could not rely on providers or staff to help them find needed services.
- An increase in public assistance programs is needed. Many services are reportedly inaccessible due to long waiting lists, bureaucracy, and/or lack of insurance or financial resources.
- Existing services were reportedly ineffective, and do not address homeless individuals’ myriad needs. Community support programs (life skills, vocational rehabilitation, job training, transportation, etc.) in addition to shelters and mental health services are needed.
- Transportation was a huge issue. Focus group members recounted the challenges of maintaining employment or going back to school without reliable transportation. Programs that provide reliable and inexpensive access to transportation are needed.
- More shelters and beds would get more homeless individuals off the streets, and reduce waiting lists. Also, revising shelter rules and regulations to be less strict would help those who work late.
- Screening and follow-up services would ensure that the homeless are getting the mental health services they need. Follow-up can also prevent future relapses.
- Many individuals felt doubly stigmatized by their mental illness and homelessness. Focus group members felt they were often treated unfairly and did not have say in their care due to preconceptions about homelessness and mental illness. Training of shelter staff, mental health providers, nurses, and police who have contact with the homeless and/or mentally ill was recommended.

Population and Prevalence of Mental Health Difficulties among the Homeless

The National Alliance to End Homelessness reported that on any given night in January 2005, 744,313 people in the United States experienced homelessness. Of those, an estimated 7,135 were living in Missouri, and of those, almost a third (an estimated 1,974 Missourians) were unsheltered and sleeping on the streets. Although the largest concentration of homeless individuals are in St. Louis City and in and around the Kansas City metropolitan area, the largest number of unsheltered homeless live in the Columbia/Boone County area, where 62% (795 individuals) of the homeless are estimated to be unsheltered on any given night. In addition, the most recent Missouri data suggests the homeless

Total Homeless: 744,313 people

The infographic displays three pie charts and a map of the United States illustrating homelessness statistics.

Homeless Status Breakdown:

- Sheltered: 56%
- Unsheltered: 44%

Individuals Status Breakdown:

- Individuals: 59%
- Persons in Families: 41%

Chronic Status Breakdown:

- Chronic: 23%
- Non-chronic: 77%

Homeless Estimates by State

The map shows the number of homeless individuals by state, color-coded by population range:

- 487–3,350 (Lightest Blue)
- 3,351–12,264 (Light Blue)
- 12,265–27,161 (Medium Blue)
- 27,162–61,094 (Dark Blue)
- 61,095–170,270 (Darkest Blue)

U.S. Homeless Estimates by State:

State	Estimate
AK	2,749
AL	4,731
AR	5,626
AZ	12,264
CA	170,270
CO	21,730
CT	5,357
DE	1,108
DC	5,518
FL	60,867
GA	27,161
HI	5,943
ID	5,424
IL	16,599
IN	9,857
IA	8,130
KS	5,278
KY	4,934
LA	5,476
MA	14,730
MD	7,995
ME	2,775
MI	26,124
MN	7,313
MO	7,135
MS	1,652
MT	1,343
NE	3,350
NH	3,233
NJ	19,385
NM	5,256
ND	655
NV	16,402
NY	61,094
OH	16,165
OK	4,869
OR	16,221
PA	15,298
RI	6,866
SC	7,958
SD	1,029
TN	8,066
TX	43,630
UT	3,104
VA	10,346
VT	927
WA	23,970
WY	487

There are also an estimated sixteen hundred chronically homeless Missourians. Chronic homelessness is defined by HUD, and refers to individuals who are homeless repeatedly or for long periods, and have a disability that makes it difficult for them to achieve stable housing (National Alliance to End Homelessness, 2007). Many of the chronic homeless are individuals who are experiencing disabling mental illness and substance use difficulties. Research estimates that two-thirds of those people with serious mental illness have at some point in their lives either experienced homelessness or have been at risk for homelessness (Tessler & Dennis, 1989). In addition, it has been reported that about 50% of all homeless adults with serious mental illness have a co-occurring substance use disorder (Fischer & Breakey, 1991). In 2001 it was reported that 28% of the sheltered homeless population in Missouri had a severe mental illness, 34% were addicted to drugs or alcohol, and 10% were both mentally ill and addicted (Gould et al., 2002).

The findings and recommendations are derived from a focus group conducted with homeless adults, an interview with an individual from a St. Louis are homeless agency, and a literature review on mental health issues specific to homeless individuals. The focus group was conducted in the St. Louis City, with 14 homeless adults who were recruited by a local mental health agency. The participants were between

the ages of 23 and 52, with an average age of 43 years. Seventy-one percent were males and 29% were females. Fifty percent of the participants had no health insurance, 29% were on Medicaid, 7% had private insurance, and 14% indicated that they had “other” insurance. Fourteen percent (14%) were Caucasian and 64% were African-American. One individual was Native-American (7%) and two (14%) marked their ethnicity as “other.”

Detailed Findings: Key Themes

A “Road Map” for Available Services. Many homeless individuals in the focus group said that they had little knowledge of the available services for substance use and mental health before they became homeless. Most knew of AA and NA, but had no knowledge of where to go for help with mental illness. Most reported that other homeless individuals, rather than agencies or providers, were the most helpful for telling them where to go to seek services. In addition, they expressed frustration that there was no one agency that could give them the information to get all the services (e.g. transportation, food, shelter, mental health, and substance abuse treatment) they need. Therefore, locating services and treatment within the community for homeless consumers and educating consumers, shelters, and the public about the available resources may alleviate these barriers. A similar recommendation was included in the needs assessment conducted by Rinck & Graybill (2005).

“...you get on a list and you wait and you wait and you wait...”

-- Homeless focus group participant

Inaccessible Services. Focus group members mentioned long waiting lists and wait times to access services. They mentioned that often the only way to get help was to say that they were a threat to themselves or others. Focus group members also admitted to relying on second-hand medication because of the wait and/or lack of resources for needed prescriptions. Recommendations made by Gould et al. (2002) included increasing the accessibility of public assistance programs to all impoverished individuals

“Services [should be] based on need instead of paper work.”

-- Key informant

by making the application process more efficient, decreasing the amount of time it takes to determine a person’s eligibility, enroll impoverished individuals in all programs for which they are eligible, and ensure public assistance programs are adjusted to a reasonable standard of need. A key informant also recommended an increase in public assistance programs; specifically, increasing access to social security benefits for the homeless population. He asserted that there were two deaths in the past year that could have easily been prevented if the individuals were receiving benefits so they could access the appropriate medical services.

Ineffective Services. Not only did the focus group members report that receiving assistance for the services they need was difficult, but they also reported that the existing services often do not address their needs. They reported that some providers will “do something” but that it isn’t usually enough to get them off the streets for good. They expressed frustration that they were placed straight into shelters, and that no one took the time to help them find the right services. One woman reported having to go to substance abuse treatment even though she never used substances, just to get services in St. Louis. Providing training (life skills, vocational rehabilitation, job training, etc.) programs that take into account individual needs was recommended by Gould et al. (2002).

"They are funding programs that don't help people."

-- Focus group member

Screening and Follow-up. Focus group participants reported a need for screening and follow-up services. Many homeless individuals continue to have undiagnosed mental health issues. Many homeless individuals at the focus group had seen severely mentally ill individuals slipping through the cracks and not receiving services, some of whom have become dangerous to

themselves or others. Conducting more screenings for homeless individuals will increase the number of individuals diagnosed and the number of homeless individuals receiving treatment for their mental illnesses. Identifying, treating, and providing follow-up services may provide the homeless population with an opportunity for recovery and progression, especially for those individuals that have severe mental illness and/or co-occurring disorders.

Transportation. Transportation was a major issue for the focus group members. They reported that transportation by van or bus was often unreliable because of inconvenient running times, schedule conflicts, and inaccessible routes (e.g., rural locations). One man reported that he was capable of working or going back to school, but that lack of transportation was a huge barrier. Regularly providing bus passes, metro links, and/or taxi fare to homeless individuals may help elevate some of these barriers.

Double Stigma. Focus group members felt a "double stigma" due to their status as both mentally ill and homeless. They felt that people in general, including mental health providers, nurses, and police, viewed them as "lazy bums." They felt that their mental health difficulties, combined with the stigma of being homeless, was impeding their efforts to get back on their feet.

"Tough love doesn't work...I've had tough love my whole life."

-- Homeless focus group participant

One woman reported that a treatment program used "tough love," focusing more on the clothing she was wearing than what would help her as an individual. Focus group members reported that many providers do not care about them or what happens to them, and providers do not give them the opportunity to participate in their own treatment. Rinck & Graybill (2005) and focus group members recommended mental health training for shelter and law enforcement staff. In addition, focus group participants mentioned training for local agency providers to reduce stigma.

Housing. Focus group members, a key informant, and Gould et al. (2002) suggested an increase in affordable housing which includes an increase in stock housing and transitional housing, so that individuals have a stable environment while they are trying to secure their own housing. Gould et al. (2002) also recommended that Shelter Plus Care for permanent housing be reauthorized. In addition, Gould et al. (2002) and Rinck & Graybill (2005) suggested that housing and community based services be incorporated into public and private institutions to help individuals during the transition from public or private institutions (i.e., jails, hospitals, mental health facilities, etc.).

Shelters. Focus group members recommended an increase in the numbers of shelters, drop in centers, and beds. In addition, they reported that the rules and regulations of the shelters were too strict. Therefore, extended shelter hours would ensure consumers have access to a bed later in the evening. Several participants experienced being late (because of job obligations) and were denied a place to sleep for the night. One man stated that it was easier to say sober when he had a place to sleep at night.

Increased Psychiatrists. Gould et al. (2002) and the key informant suggested that incentives be provided to increase the number of psychiatrists available to work with homeless consumers.

Prevention. Gould et al. (2002) recommended an increase in funds to set up programs to reduce/prevent the loss of current residences. Another recommendation was that a statewide data information system be set up to monitor homelessness. In addition, focus group members suggested providing rehabilitative services and intensive community support networks to reduce homelessness. Lastly, Rinck & Graybill (2005) suggested creating prevention and intervention programs for children of homeless consumers.

Lesbian, Gay, Bi-sexual, Transgender Community

“There is a shortage of folks who work in this area.”

Summary of Findings and Recommendations

Findings and recommendations presented are derived from an interview with a registered nurse who specializes in LGBT issues as well as from literature on the topic.

- LGBT individuals with mental health issues face double stigma, the stigma associated with being LGBT and the stigma associated with having a mental health problem. Stigma exists not only among the general population but also among physical and mental health providers. Stigma reduction would improve persons in the LGBT community's ability to access more health care, including mental health care.
- LGBT youth could benefit from mental health education and learning about resources to help educate them to know where to go if they suspect they may be suffering from a mental health issue.
- The LGBT community and the population at large could benefit from general positive public health messaging (on-line messages, magazines, TV, billboards). Public health messages could contain information regarding healthy behaviors, including substance use and safe sexual practices, mental illness, and where to go to get help for a mental illness.
- Insurance and MO Health Care coverage is a significant barrier to accessing care among LGBT individuals. There are many limitations in the current MO HealthNet system as well as with private health care insurance for LGBT individuals. It can be difficult to get psychiatric medications paid for by MO HealthNet.

Population and Prevalence of Mental Health Difficulties among Persons Who are Lesbian, Gay, Bi-sexual, and Transgender

The gay population in Missouri is growing. An estimated 161,000 gay individuals reside in Missouri, and this trend is predicted to continue to increase (Lysen, 2007). According to Huygen (2006), research indicates that gay men and lesbians are at greater risk for psychiatric morbidity than heterosexuals, but there is not a lot of literature on the topic. Huygen reports that research has indicated that bisexually-identified youth are at higher risk for suicide (Ramafedi, French, Story, Resnick, & Blum, 1998). This is similar for homosexually-oriented youth (Russell & Joyner, 2001) and for adults (Gilman, Cochran, Mays, et al., 2001). Gilman and colleagues also found that people reporting same-sex partners were more likely to experience symptoms of psychiatric problems and suicide more so than their heterosexual counterparts. Huygen acknowledges that LGBT individuals may have higher resilience due to the stresses they have to face in their daily lives.

Approximately 3-5% of the U.S. population identifies as gay or lesbian, yet up to 40% of homeless youth identify as lesbian, gay, bisexual, and/or transgender (www.thetaskforce.org/node/2114/print). LGBT youth also report experiences discrimination and harassment at shelters and service providers. Clements-

Noelle, Mars, Guzman, and Katz (2001) stated that higher rates of attempted suicide among gay youths compared with heterosexual youths may be partially due to discrimination and victimization.

Data Sources

Data from this section comes from a review of secondary sources and interviews with a registered nurse and medical director at a clinic that specializes in serving LGBT youth and adults.

Detailed Findings: Key Themes

Access to Care and Resources. There is a shortage of providers who specialize in LGBT issues in Missouri. The clinician we spoke with sees patients from all over the state, since there are so few providers. Not only is there limited access to care and resources, many public health messages are not directed toward LGBT individuals. There is an extreme shortage of professionals who can even take patients who can pay for services within this community, and if the consumer has no money, they have even less access to service.

“There is a limited number of providers who feel comfortable treating the LGBT community.”

-- Interview with registered nurse serving LGBT community

Access to Insurance. Insurance and MO HealthNet coverage was reported as a significant barrier to accessing care among LGBT individuals. There are many limitations in the current MO HealthNet system as well as with private health care insurance for LGBT individuals.

Stigma. LGBT individuals with mental illness suffer from two types of stigma, both stigmatization due to sexual orientation and stigmatization due to mental illness. Members of the LGBT community may feel stigmatized at their workplace as well as in their communities. Stigma is stronger for transgender individuals who are often rejected by persons in the gay and lesbian community (personal communication, 2007).

Training in Schools. Diversity training for students in elementary school and high school would be helpful in fighting stigma. Public Service Announcements (PSAs) would also be useful in educating the public, and thus, reducing stigma.

CHAPTER SIX

SUBSTANCE ABUSE AND MENTAL HEALTH PROVIDER AGENCY SURVEYS: CONSUMER NEEDS AND RESOURCES

Background

Seventy-four mental health and substance abuse agencies completed a web-based survey designed to assess the resources of agencies and the needs of consumers of mental health and substance abuse services. While drawn from a Missouri Department of Mental Health (DMH)-contractor provider list, DMH also has contracts with other entities, including MO HealthNet, other state departments, Medicare employer-sponsored plans, etc. The majority of agencies (78%) served both persons with mental illness and substance abuse problems, 74% were primarily not-for-profit organizations, and half (50%) were located in urban areas. Approximately 74% of agencies provided out-patient services, and 54% offered case management. Approximately 13% of the sample was Non-Medicaid C-STAR and MO HealthNet providers.

Major Findings

- When asked what one change to the mental health system they would advocate for, the most common answers fell into the following categories: co-occurring disorders training and treatment, services to the under-insured, better co-ordination of services, community support services, greater consumer choice, more funding for services, and more long term care services.
- Co-occurring disorders training and treatment was the #1-ranked change for which providers said they would advocate. Many providers reported that cross training and certification of substance abuse and mental health professionals are needed, as well as better co-ordinated care for severely ill clients.
- When mental health and substance abuse agencies were asked to rate the needs for individuals with mental illness and substance use, the top five ranked needs were: transportation assistance, ongoing recovery/support services, provider co-occurring disorder training, expanded school-based mental health services, and better evaluation of persons with co-occurring disorders.
- Other highly ranked (#5-#10) needs included: residential and outpatient co-occurring treatment providers, housing and employment assistance, and early intervention.
- Overall, themes revolved around community and recovery supports, better treatment for co-occurring disorders, and early intervention as the most pressing needs.

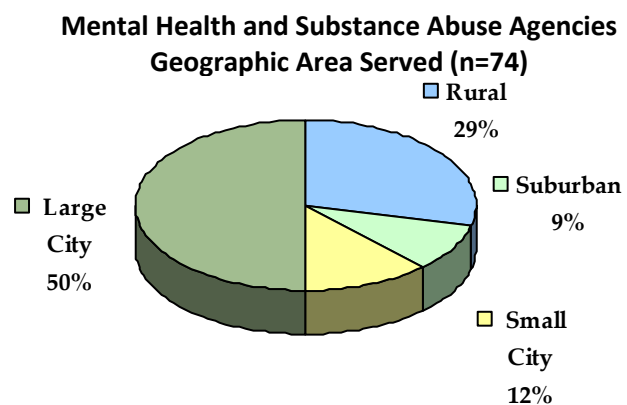
- The majority (82%) of mental health and substance abuse agencies reported using Evidence-based Practices (EBPs), with the most commonly used EBP being Cognitive Behavior Therapies (n=49, 88% of agencies who reported using EBPs), Motivational Interviewing (n=37, 63%), and Medication Management (n=35, 61%). All were rated as “very effective” on average, strongly suggesting that other mental health and substance abuse agencies may also benefit from the use of these EBPs.

Mental Health and Substance Abuse Survey Response

Of the 129 substance abuse and mental health agencies asked to participate in the survey, 74 responded, a response rate of 57%. Of the agencies responding, four out of five (78%) characterized their agency as one that serves consumers with both mental illness and substance use disorders. Very few described their agency as serving only those with mental illness (10%) or only those with substance use disorders (12%).

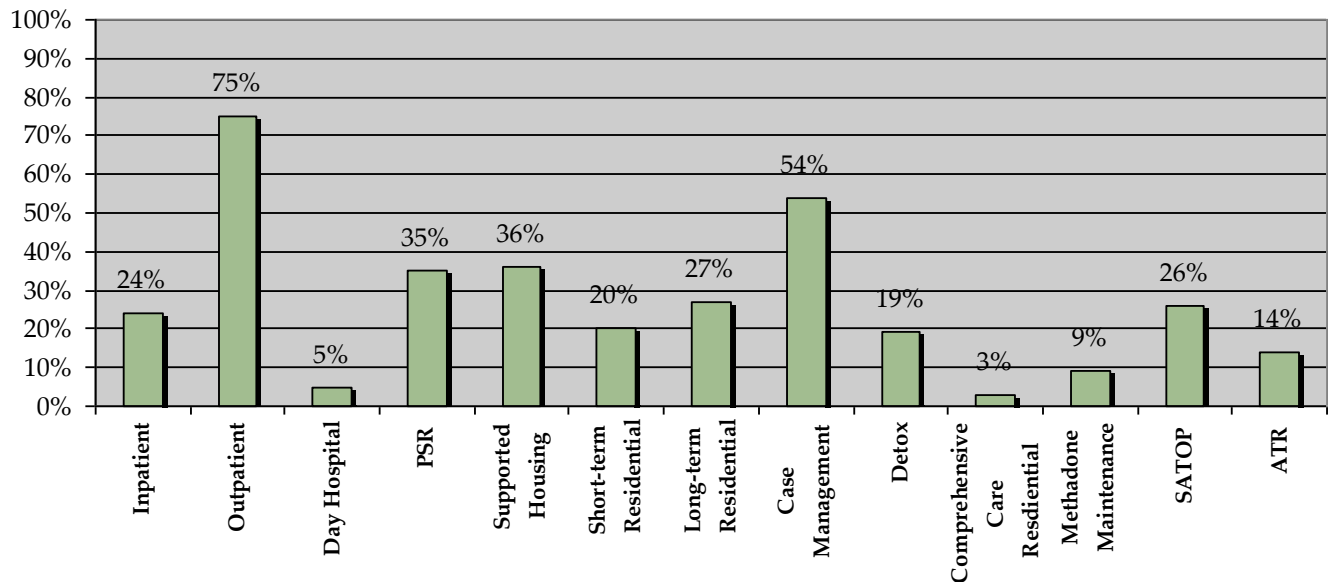
Agency Characteristics

Agencies were asked basic questions regarding the type of business entity they are, their appointment availability, and the geographic areas they serve. The large majority of agencies (74%) were private, not-for-profit agencies, while 18% were for-profit. None were solo private agencies. Half serve urban areas, although there was a good representation of agencies that primarily serve rural areas as well (29%). Almost all agencies offer evening (87%) or weekend (79%) appointments.



Agencies were also given a list of agency classifications and asked to check all that apply to them. As shown below, approximately 74% of agencies provided outpatient services, and 54% offered case management. Approximately 13% of the providers were General C-STAR POS and Mo HealthNet providers.

Agency Classifications (n=74)



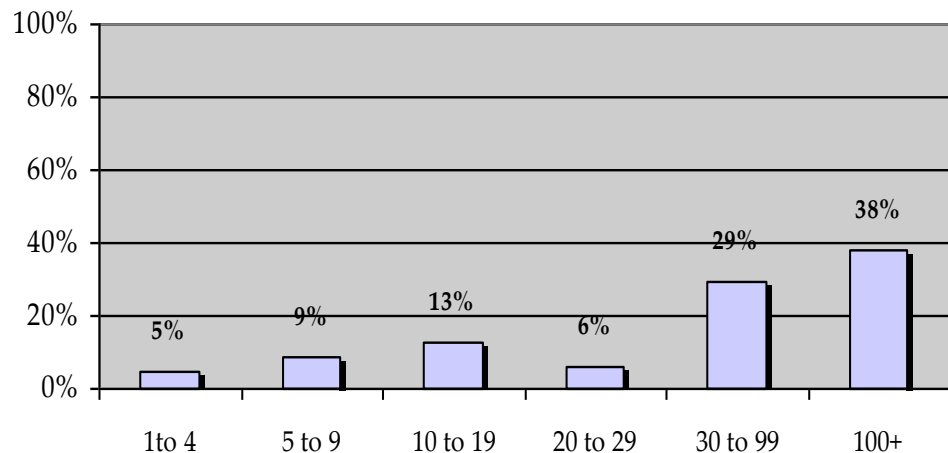
Workforce

Most mental health and substance abuse agencies surveyed were medium or large sized agencies. The chart below shows 67% had 30 or more employees.

The agencies were also asked what types of employees they had in-house to provide services (see table next page; highest frequencies are in bold). Most agencies had at least one social worker or counselor, while a little more than half kept a psychologist or psychiatrist on staff. Paraprofessionals and case managers were the most common employees, with approximately a third of agencies employing more than 16. Physicians, nurses, and vocational counselors were least likely to be employed in house.

Agencies were also asked which professionals they contracted with to provide services. With the exception of psychiatrists (54.1%

Number of Agency Employees (n=74)



contracted with at least one psychiatrist), contracting was a relatively uncommon practice, particularly with paraprofessionals and case managers, which are commonly hired in-house. It was also relatively uncommon to contract for nurse practitioners, registered nurses, vocational/education counselors, and certified substance abuse counselors. Agencies tended to contract with professionals who may be

prohibitively expensive to keep in-house--most commonly psychiatrists, but also physicians (17.3% contracted with at least one physician), and psychologists (13.7% contracted with at least one).

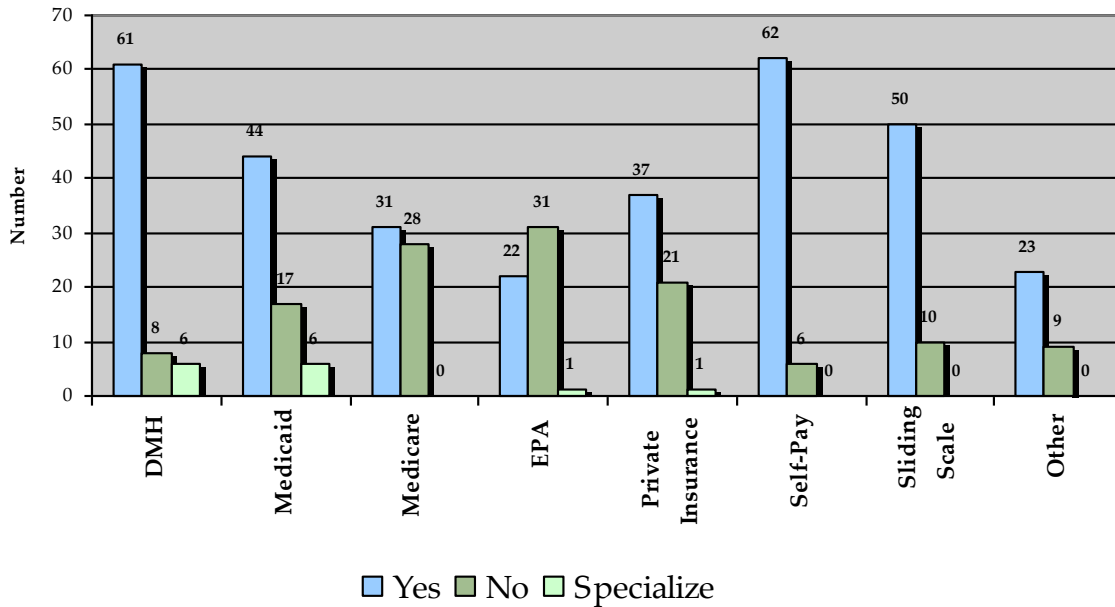
Substance Abuse and Mental Health Care Agencies Types and Numbers of Professionals In House (n=74)

	0	1	2-3	4-7	8-15	16+
Psychologists (n=55)	49.1%	18.2%	18.2%	10.9%	0.0%	3.6%
Psychiatrists (n=59)	44.1%	15.3%	18.6%	10.2%	8.5%	3.4%
Licensed clinical social workers (n=66)	13.6%	15.2%	21.2%	24.2%	13.6%	12.1%
Licensed counselors (n=63)	19.0%	11.1%	14.3%	27.0%	22.2%	6.3%
Paraprofessionals (n=56)	30.4%	7.1%	12.5%	8.9%	8.9%	32.1%
Case managers (n=67)	25.4%	6.0%	3.0%	17.9%	11.9%	35.8%
Certified substance abuse counselors (n=70)	18.6%	12.9%	15.7%	27.1%	15.7%	10.0%
Nurse practitioners (n=53)	62.3%	13.2%	5.7%	15.1%	1.9%	1.9%
Registered nurses (n=67)	33.8%	20.6%	22.1%	7.4%	10.3%	5.9%
Licensed practical nurses (n=59)	49.2%	18.6%	15.3%	10.2%	3.4%	3.4%
General practitioner physicians (n=56)	76.8%	14.3%	0.0%	3.6%	3.6%	1.8%
Vocational/education counselors (n=55)	69.1%	10.9%	5.5%	7.3%	1.8%	5.5%

Sources of Consumer Funding

Agencies were asked to identify the funding sources from which consumer services are paid. If an agency specialized in consumers receiving a certain type of funding, they were also asked to choose the "Specialize" box. Almost all agencies reported that their consumers receive funding from the DMH (61 agencies, 88% of those who responded to the question), an unsurprising finding given that the agencies were chosen from a list of DMH contracted providers. Self-pay and sliding scale payments were also commonly reported sources of funding. Other sources of funding included grants, the Children's Division, and mental health tax levees (see chart below).

Sources of Consumer Funding (n=74)



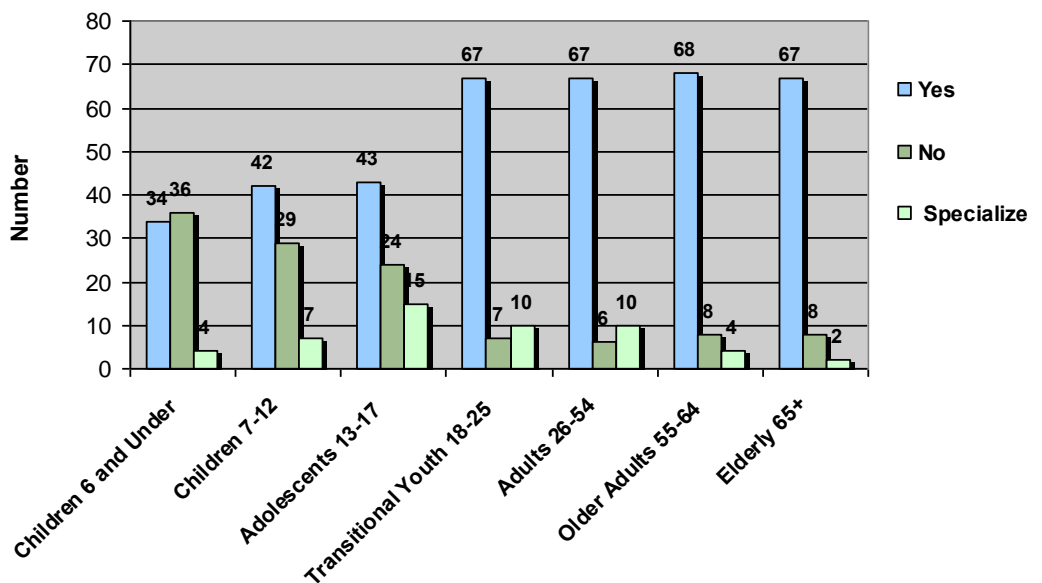
Consumer Characteristics

Agencies were asked various questions with the goal of understanding the populations they serve. Agencies were not only asked whether they served consumers with particular characteristics, but they were also asked to check “Specialize” if they specialized in serving that type of consumer.

Demographic Characteristics

The ages served by agencies are shown at right. Almost all agencies served adults, and approximately half served children and adolescents. The least commonly served group was children under the age of 5 years

Ages Served by Agencies (n=74)



old. The most common age specialization was adolescents aged 13-17. Very few agencies who responded to the survey specialized in elderly adults. Agencies were also asked what genders they served. Almost all agencies served both males and females with the exception of two agencies: one only served females and one only served males. Four agencies (4.9%) reported specializing in serving males and seven agencies (8.6%) specialized in serving women.

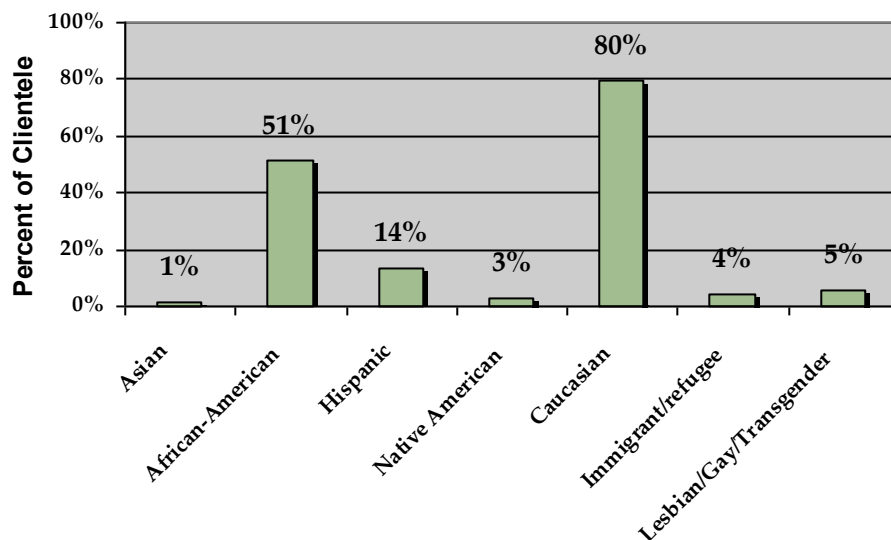
Cultural Characteristics

Ethnicity/Race/Sexual Orientation

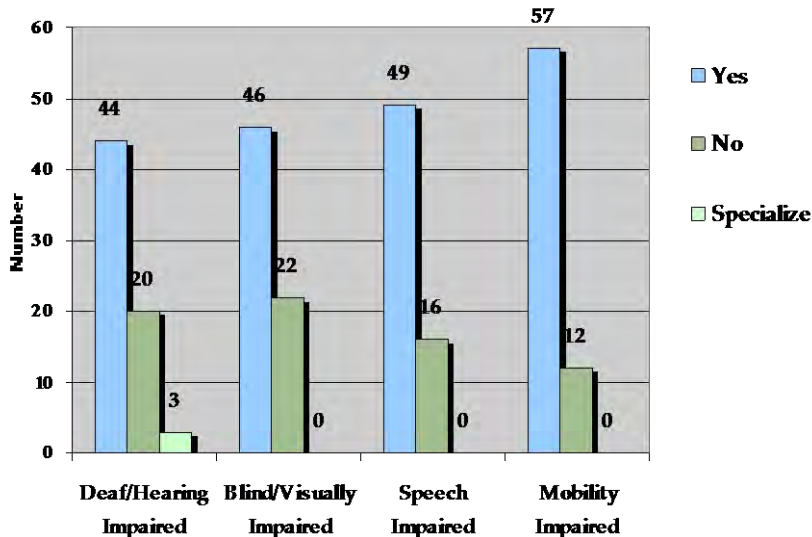
We were interested in knowing not only the cultural characteristics of the population, but also to what extent the treatment staff shares the cultural background of the treatment population. “Cultural” was broadly defined as ethnicity, gender, age, and sexual orientation. As shown in the chart at right, approximately 80% of agencies reported that Caucasian clients make up more than 20% of their clientele. About 50% reported that African-American individuals were more than 20% of their clientele. In terms of treatment staff, a large majority of agencies (70%) reported that around 75% or more of their treatment staff shares the cultural background of the individuals seeking treatment. About 17% of agencies reported that around 25% or less of their treatment staff shares the cultural background of the clientele.

Agencies were also asked about the languages their programs can support. The most commonly supported language was Spanish (n=24, about 1/3 of agencies). No other language was commonly offered. Several agencies (n=9)

Cultural Characteristics of Consumers Served by Agencies (n=74)



Agencies Serving and Specializing in Serving Clients with a Physical or Sensory Impairment (n=74)



reported contracting out for language interpretation/translation services as needed.

Physical/Sensory Impairment

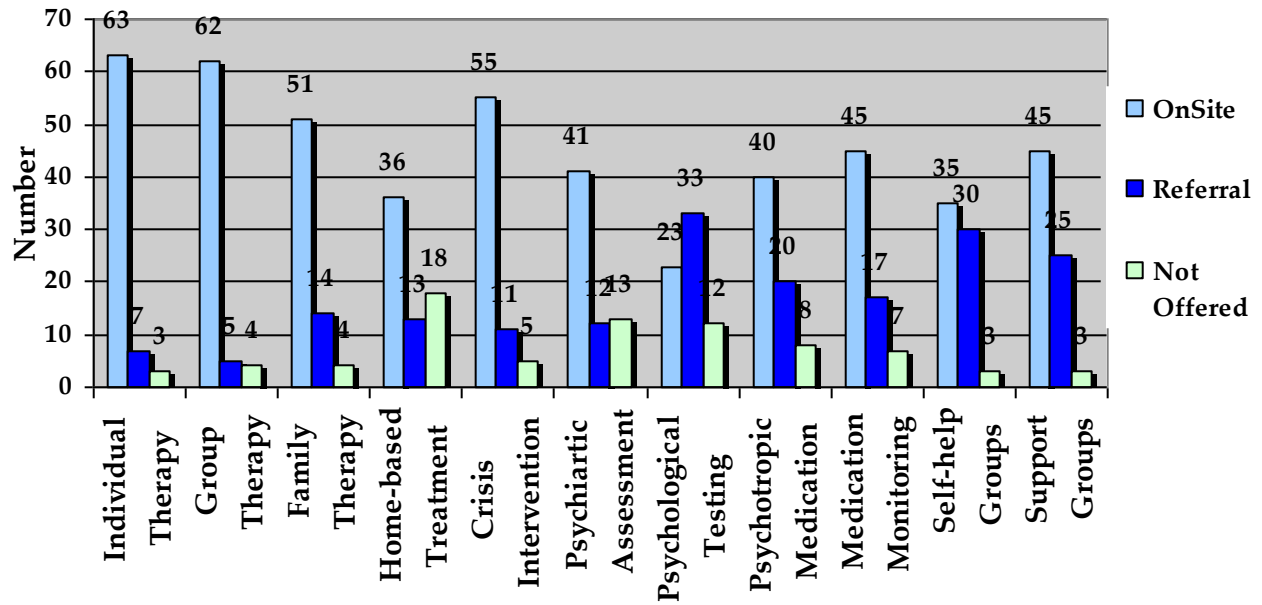
Mental health and substance abuse agencies were asked if they serve individuals with specific impairments, and if they specialize in serving any particular population with various sensory and physical impairments. Results indicate that agencies are more likely to serve individuals with mobility impairments than sensory impairments. Almost three out of four agencies serve individuals with mobility impairments versus approximately 60% that serve the deaf or hard of hearing. While the deaf and hard of hearing were served by the lowest number of agencies overall, three agencies specialized in serving that population. There were no agencies that specialized in serving individuals with speech, visual, or mobile impairments specifically. Nonetheless, a majority of agencies reported serving those populations.

Agency Services

Agencies were given a large list of services, and asked which ones they offer on-site and by referral. For purposes of presentation, services are divided into several categories: Psychological Services, Addiction/Substance Abuse Services, Educational and Vocational Services, Medical Services, Social Services, Prevention Services, and Other Support Services.

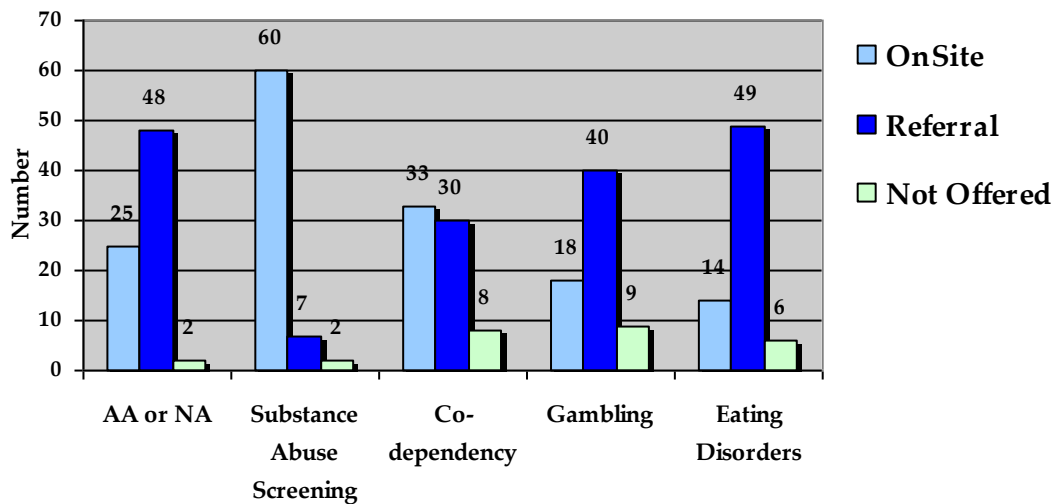
Psychiatric Services

Psychiatric services included basic mental health services such as therapy, support groups, psychological assessment, and psychotropic medication. The results are shown in the chart below. Of the 74 substance abuse and mental health care agencies surveyed, most (85% and 84% respectively) offered individual and group counseling or therapy on-site, and most of those who did not offered referrals to therapy. The least commonly offered service on site was psychological testing -- 13 sites did not even offer it by referral. Home-based treatment and psychiatric assessment were also uncommonly offered on-site, and several agencies did not offer them even by referral.



Addiction/Substance Abuse Services

As is shown in the chart below, most, but not all, mental health and substance abuse agencies offer some kind of substance abuse screening for their consumers. Most of the other services are offered either on-site or by referral.

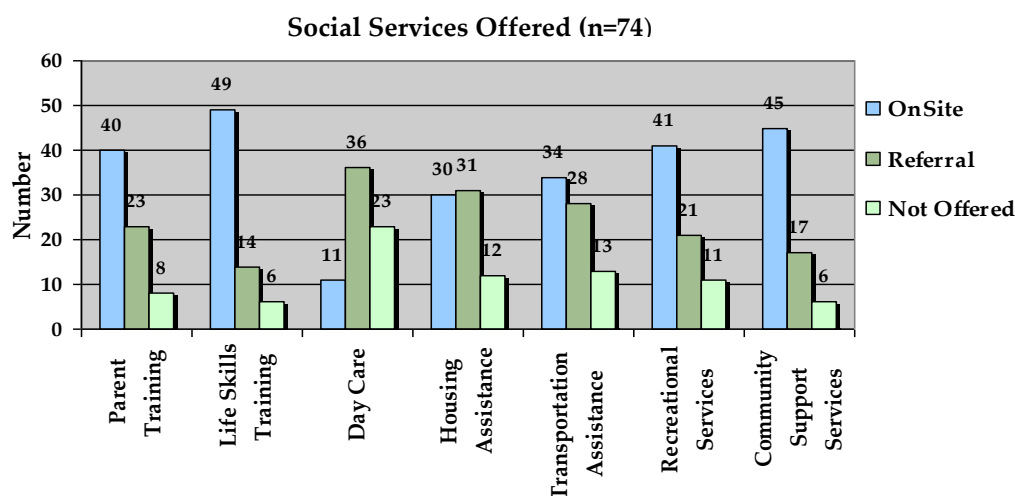


Educational and Vocational Services

Most sites (about two thirds) offer vocational services upon referral only. Vocational counseling and tutoring were the most commonly offered on-site services, offered by 24% and 30% of sites, respectively. Vocational job training, job placement, and vocational testing were offered on-site by about 18% of sites.

Social Services

The majority of sites offered parent training, life skills training, recreational services, and community support services on-site. Housing and transportation assistance were offered on-site by less than half of all sites. Day care was offered least, with 47 out of 74 sites (64%) offering it either on-site or by referral.



Prevention Services

It was common for sites to offer substance abuse education, suicide prevention education, social skills training, and screening on-site. Approximately one-third of sites offered prevention programming in or after school. Very few sites offered mentoring on site.

Medical Services

Sites were asked what kind of medical services they offered to their consumers. Approximately 26% of sites (20 sites) offered on-site medical exams upon admission, 46% (34 sites) through referral, and 23% (17 sites) did not offer them at all. Fifteen sites (20%) offered an annual medical exam on site, 39 (53%) offered them through referral, and 15 (20%) did not offer them at all.

Other Support Services

Thirty-five sites (46%) offered psychosocial rehabilitation on-site, and 20 (27%) offered it through referral. Benefit acquisition assistance was offered on-site by 32 (43%) sites, school-based services were offered by 26 (35%) sites, children services were offered on-site by 32 (43%) sites, faith-based services were offered by 9 (12%) sites, and legal services were offered on site by 6 (8%) sites--(5 offered both legal advocacy and legal service counseling and 1 offered legal service counseling only).

Agency Ranking of Needs

Ranking of Needs of Individuals with Mental Illness/Substance Use Disorders

Substance abuse and mental health agencies were asked what they felt were the strongest needs of individuals with mental illness and substance use disorders. "Strength of Need" was determined through use of response options on a Likert Scale, where 1 = "No need at all" and 4 = "Critical need." The mean of all respondents' answers was taken to get the strength of need for that question. Respondents had a tendency to rate all needs as "High Need. The following needs emerged as being most critical (list is not rank ordered because many needs were found to be identically strong.

- Single point of entry into system
- Transportation assistance/more transportation
- Ongoing recovery/support services
- Provider co-occurring disorder training
- Residential co-occurring treatment providers
- Expanded school-based mental health services
- Housing assistance
- Employment assistance
- Better evaluation of persons with co-occurring disorders
- Outpatient co-occurring treatment providers

Respondents also had an opportunity to list other needs if they didn't see it on our list. The most commonly listed other needs include medical detoxification, prevention programs, more staff (and not more agencies), more child psychiatrists, and co-occurring treatment services.

Mental Health and Substance Abuse Agency Ratings of Needs of Individuals with Mental Illness and Substance Use Disorders (n=74)

	No Need At All	Low Need	High Need	Critical Need	Don't Know	Strength of Need (1-4 Scale)
Single point of entry into system	12.9%	17.1%	30.0%	25.7%	14.3%	3.82
More available transportation	1.5%	8.8%	30.9%	57.4%	1.5%	3.47
Transportation Assistance	1.4%	7.2%	40.6%	47.8%	2.9%	3.40
Ongoing recovery/support services	0.0%	7.1%	51.4%	38.6%	2.9%	3.33
Provider co-occurring disorder training	1.5%	10.3%	39.7%	42.6%	5.9%	3.31
Expanded school-based mental health services	2.9%	4.3%	43.5%	34.8%	14.5%	3.30
Residential co-occurring treatment providers	1.5%	11.8%	39.7%	39.7%	7.4%	3.30
Housing assistance	1.4%	7.2%	50.7%	36.2%	4.3%	3.28
Employment assistance	1.4%	7.2%	52.2%	36.2%	2.9%	3.28
Better evaluation of persons with co-occurring disorders	1.5%	4.4%	55.9%	35.3%	2.9%	3.28
Outpatient co-occurring treatment providers	1.5%	7.5%	55.2%	32.8%	3.0%	3.23
Early intervention/screening	1.5%	7.4%	47.1%	26.5%	17.6%	3.21
Self-help/support groups specific to co-occurring disorders	1.5%	10.3%	48.5%	32.4%	7.4%	3.20
Public awareness/education	0.0%	5.6%	66.2%	22.5%	2.8%	3.19
Transitional services (inpatient to outpatient)	1.4%	5.8%	58.0%	26.1%	8.7%	3.19
Substance abuse education services	2.9%	7.2%	49.3%	27.5%	13.0%	3.18
Inpatient co-occurring treatment providers	1.5%	17.6%	33.8%	36.8%	10.3%	3.18
Residential treatment programs	0.0%	14.1%	47.9%	32.4%	5.6%	3.17
Fewer days from initial contact until appointment	4.3%	7.2%	59.4%	27.5%	1.4%	3.12
Medication monitoring	1.4%	11.6%	40.6%	23.2%	23.2%	3.11
Transitional support (adolescent to adult system)	1.4%	13.0%	43.5%	24.6%	17.4%	3.11
Inpatient treatment programs for children	1.4%	12.9%	40.0%	22.9%	22.9%	3.09
Detox Services	2.8%	14.1%	47.9%	26.8%	8.5%	3.09
Family support groups	1.4%	8.7%	62.3%	18.8%	8.7%	3.08
Youth social skills development services	1.4%	7.2%	58.0%	15.9%	17.4%	3.08
Inpatient treatment programs for adults	2.8%	15.5%	49.3%	26.8%	5.6%	3.06
Additional psychiatrists	5.8%	18.8%	33.3%	36.2%	5.8%	3.06
Childcare during treatment	1.4%	12.9%	57.1%	20.0%	8.6%	3.06
Inpatient beds	1.4%	20.3%	33.3%	26.1%	18.8%	3.04

	No Need At All	Low Need	High Need	Critical Need	Don't Know	Strength of Need (1-4 Scale)
Crisis intervention	1.4%	15.5%	57.7%	18.3%	7.0%	3.00
Self-help/support groups	0.0%	16.9%	64.8%	15.5%	2.8%	2.99
Suicide Prevention Services	0.0%	17.1%	60.0%	11.4%	11.4%	2.93
Suicide prevention	1.4%	13.0%	56.5%	10.1%	18.8%	2.93
Outpatient child/adolescent treatment providers	1.5%	19.1%	47.1%	14.7%	17.6%	2.91
Residential child/adolescent treatment providers	1.4%	20.3%	44.9%	13.0%	20.3%	2.88
Drop-in clinics	1.4%	31.0%	35.2%	21.1%	11.3%	2.86
Inpatient child/adolescent treatment providers	1.4%	23.2%	39.1%	14.5%	21.7%	2.86
Home-based services	4.3%	29.0%	40.6%	18.8%	7.2%	2.80
Peer counseling programs	4.3%	18.8%	44.9%	11.6%	20.3%	2.80
Day Treatment/partial hospitalization	0.0%	28.2%	47.9%	11.3%	12.7%	2.79
Respite	1.4%	21.4%	51.4%	7.1%	18.6%	2.79
Evening or Saturday appointment times	4.3%	34.8%	39.1%	13.0%	2.9%	2.78
Meal assistance	1.4%	36.2%	39.1%	5.8%	17.4%	2.60
Additional providers/agencies	10.1%	21.7%	60.9%	8.7%	4.3%	2.57
One statewide crisis hotline	14.7%	33.8%	27.9%	11.8%	11.8%	2.44

If you were to advocate for one change to the mental health care system, what would it be?

In order to further assess the needs of substance abuse and mental health agencies, respondents were asked to describe what change they would advocate for if they could only choose one issue. Sixty-nine individuals responded to the question. Analysis of the responses indicates that answers revolved around several key issues.

“One change needed in the mental health system is cross training and certification of ADA professionals and CPS professionals.”

-- Mental Health/Substance Abuse Agency Respondent

Co-occurring Disorders (n=12)

The number one change requested by respondents (12 individuals) was to improve services for individuals with co-occurring disorders. Several providers felt that cross training and certification of mental health and substance abuse providers are needed. Providers reported that there are not enough places to refer co-occurring clients, and that care for these individuals is not coordinated well. One provider felt

that the CPR service menu should include reimbursement for services provided to consumers with co-occurring disorders, and another person mentioned blending funding streams. Lack of housing and inpatient treatment for these individuals was also a concern.

Services to Under-insured (n=10)

Providers see a great need for DMH to make mental health services accessible for individuals who are under-insured or without insurance. Many of these suggestions focused on expanding MO HealthNet coverage beyond current levels. In addition, providers felt that their rates should increase and that benefits under MO HealthNet should be broadened.

“Make mental health/psychiatric treatment services more available for the “walking wounded” those without a serious mental illness, without Medicaid or some other form of health insurance but who have a mental illness that makes their chances of sustained recovery from AOD disorders more challenging.”

-- Mental Health/Substance Abuse Agency Respondent

Coordination of Services (n=8)

Related to the issue of co-occurring disorders, providers believe that services between DMH divisions and between state departments need to be better coordinated. A few providers suggested this could be done by integrated treatment planning between divisions, and one person suggested that the Division of Alcohol and Drug Abuse (ADA) and the Division of Comprehensive Psychiatric Services (CPS) be combined. Another felt that each consumer should have only one caseworker arranging and coordinating all their care.

Community Supports (n=5)

A number of providers recommended that more community supports be available to consumers so that they might have access to affordable transportation, employment, and housing. One individual felt that the mental health service community should be more involved in community organizations such as churches.

More Consumer Choice/Consumer Driven (n=6)

Providers felt that consumers should have greater choice and say in their own care. Some providers suggested a more flexible use of treatment dollars to enable them to better individualize treatment.

“Allow the providers that have good outcomes and who consistently provide quality services to expand those services so that all consumers have a choice as to who provides their services and funding to drive those services. Level the playing field among the CMHC and the affiliates.”

-- Mental Health/Substance Abuse Agency Respondent

More In-patient and Residential Care (n=5)

A number of providers recommended that more in-patient and residential beds be made available for the seriously mentally ill. One individual suggested that the system should move from an acute care model to a chronic care model with funding for long-term support.

Other Suggestions

There were a number of other suggestions given by mental health and substance abuse agency respondents that did not fall into the above categories. Among those, the most common were a desire to localize and privatize services (or increase collaboration with private agencies) and a desire for more money for prevention. Other suggestions included more psychiatrists, better integration of physical and mental health, parity for mental health and substance abuse, shorter waiting lists, and an increase in reimbursement rates to providers.

Effectiveness and Use of Evidence-Based Practices by Mental Health and Substance Abuse Agencies

All agencies were asked if they used EBP's in their facilities. Of the 68 mental health and substance abuse agencies that responded to the question, 82% reported that they use EBP's (for a total of 56 agencies). Agencies were also asked whether they use various selected EBP's, and if so, to rate their effectiveness. The list of EBP's, shown below, was based on a list developed by Washington State, and modified by researchers at the Missouri Institute of Mental Health (MIMH) with assistance from DMH. MIMH researchers reviewed prevention literature and added various prevention EBP's not on the original list. In addition, EBP's of interest to DMH were added.

The table below shows all EBP's used by five or more agencies, and their ratings. Of the 47 EBP's agencies could choose from, five or more agencies used 32 (65%) of the EBP's listed. The most commonly used EBP's were Cognitive Behavior Therapies (n=49, 88% of agencies using EBP's), Life Skills Training (n=38, 68%), Motivational Interviewing (n=37, 63%), and Medication Management (n=35, 61%). As can also be seen in the table, each EBP's was also given a number meant to indicate its "effectiveness," as judged by agency respondents. Effectiveness was determined by putting the response options on a Likert Scale, where 1 = "A little effective" and 4 = "Extremely effective." The mean of all respondents' answers was taken to get the overall effectiveness for that EBP. The resulting number allowed a ranking as to which EBP's were rated as most and least effective by the agencies that use them. A number of EBP's were used by very few agencies, so their ratings may be a less reliable indicator of effectiveness in MR/DD agencies than those with more agencies using them. Furthermore, the fact that an EBP is used by a large number of agencies may, in some cases, be a testament to its success with the MR/DD population. In fact, the two most commonly used EBP's, Cognitive Behavior Therapies and Motivational Interviewing, were among the highest rated EBP's as well. The top three rated EBP's were Trauma Recovery and Empowerment Treatment (TREM; n=6), Supported Employment (n=17), and Cognitive Behavior Therapies (n=49).

Effectiveness and Use of Selected Evidenced Based Practices by Mental Health and Substance Abuse Agencies (n=56)

	Number who Offer EBP	A Little Effective	Somewhat Effective	Very Effective	Extremely Effective	Overall Effectiveness of EBP (1-4 Scale)
Aggression Replacement Training	10	20.0%	40.0%	40.0%	0.0%	2.20
Assertive Community Treatment (ACT/PACT)	10	0.0%	40.0%	30.0%	30.0%	2.90
Behavioral Treatment for Substance Abuse in Schizophrenia	10	10.0%	50.0%	30.0%	10.0%	2.40
Big Brothers/Big Sisters	5	20.0%	20.0%	60.0%	0.0%	2.40
Brief Strategic Family Therapy	22	4.5%	31.8%	54.5%	9.1%	2.68
Cognitive Behavior Therapies (CBT)	49	0.0%	18.4%	63.3%	18.4%	3.00
Contingency Management (co-occurring)	17	5.9%	35.3%	35.3%	23.5%	2.77
Dialectical Behavioral Therapy (DBT)	16	12.5%	31.3%	37.5%	18.8%	2.62
Family Psycho education	24	8.3%	37.5%	41.7%	12.5%	2.58
Functional Family Therapy	17	5.9%	23.5%	52.9%	17.6%	2.82
Illness Self-Management/Illness Management and Recovery	14	14.3%	42.9%	42.9%	0.0%	2.29
Integrated Dual Diagnosis Treatment	27	7.4%	11.1%	59.3%	22.2%	2.96
Interpersonal Therapy	20	5.0%	55.0%	30.0%	10.0%	2.45
Life Skills Training	38	5.3%	42.1%	44.7%	7.9%	2.55
Medication Management	35	2.9%	25.7%	48.6%	22.9%	2.91
Motivational Enhancement Therapy (MET)	17	5.9%	41.2%	35.3%	17.6%	2.65
Motivational Interviewing	37	8.1%	29.7%	37.8%	24.3%	2.78
Multi-Family Group Treatment (MFG)	5	20.0%	80.0%	0.0%	0.0%	1.80
Multidimensional Family Therapy	5	20.0%	20.0%	40.0%	20.0%	2.60
Multi-systemic Therapy	13	7.7%	46.2%	30.8%	15.4%	2.54
Parent-Child Interaction Therapy	12	8.3%	25.0%	58.3%	8.3%	2.67
Peer Support	24	0.0%	37.5%	45.8%	16.7%	2.79
Person Centered Planning (PCP)	12	8.3%	8.3%	75.0%	8.3%	2.83
Positive Behavior Supports	17	0.0%	17.6%	64.7%	17.6%	3.00
Promoting Alternative Thinking Strategies (PATH)	6	0.0%	0.0%	33.3%	66.7%	2.67
Seeking Safety: A Psychotherapy for Trauma/PTSD and Substance Abuse	11	9.1%	27.3%	45.5%	18.2%	2.73
Signs of Suicide (SOS)	8	12.5%	62.5%	25.0%	0.0%	2.12
Strengthening Families Program (SFP)	7	0.0%	42.9%	42.9%	14.3%	2.71
Supported Employment	17	0.0%	17.6%	52.9%	29.4%	3.11
Supported Housing	20	5.0%	30.0%	45.0%	20.0%	2.80
Therapeutic Foster Care	7	14.3%	28.6%	28.6%	28.6%	2.71
Trauma Recovery and Empowerment Treatment (TREM)	6	16.7%	0.0%	50.0%	33.3%	3.17

CHAPTER SEVEN

MENTAL RETARDATION/DEVELOPMENTAL DISABILITIES PROVIDER AGENCY SURVEY

Background

One hundred and eleven Department of Mental Health (DMH)-contracted MR/DD agencies completed a web-based survey designed to assess the resources of the Division of Mental Retardation/Developmental Disabilities (MR/DD) agencies and the needs of consumers of MR/DD services. The agencies were primarily not-for-profit organizations, and almost half (44%) were located in rural areas. The most commonly offered services on-site were social skills training (68%), life skills training (66%), community supports (66%), recreation (64%), transportation (61%), and medication monitoring (46%).

Major Findings

- When asked what one change to the mental health system they would advocate for, the most common answers fell into the following categories: improved financing, better coordination and consistency of services, consumer-driven care, better pay for providers and staff, community support services, and psychiatric services.
- Overall, there was a strong feeling among agency respondents that the relationship between DMH and community providers needed to be improved. Respondents felt that lack of clarity regarding regulations and expectations, bureaucratic red tape, and lack of consistency between regional centers was severely limiting their ability to provide quality consumer-driven care.
- The highest ranked needs for individuals with mental retardation/developmental disabilities were housing, behavior management services, transportation, and employment.
- Housing is perhaps one of the most important issues for those who serve individuals with mental retardation/developmental disabilities. The #1 need as reported by agencies was shorter waiting lists for housing, and second ranked need was affordable housing (tied for #2).
- There is also a very high need for behavior management services, a need tied with affordable housing as second most critical.
- Although transportation was offered by 61% of agencies (indicating that some need is being met), they still reported a need for more convenient (#4) and affordable transportation (ranked #8) for those with mental retardation/developmental disabilities. Handicapped accessible public transportation was ranked #9.
- Employment came up many times on the list of needs. Agencies reported that those with mental retardation/developmental disabilities need more employment opportunities (#6) and better paying jobs (#7). More employment supports was also a highly ranked need (#10).
- Slightly more than half (56%) of MR/DD agencies reported using Evidence-based Practices (EBPs), with the most commonly used EBP being Positive Behavior Supports (n=49, 89% of agencies who reported using EBPs) and Person Centered Planning (n=47, 85%). Both were rated

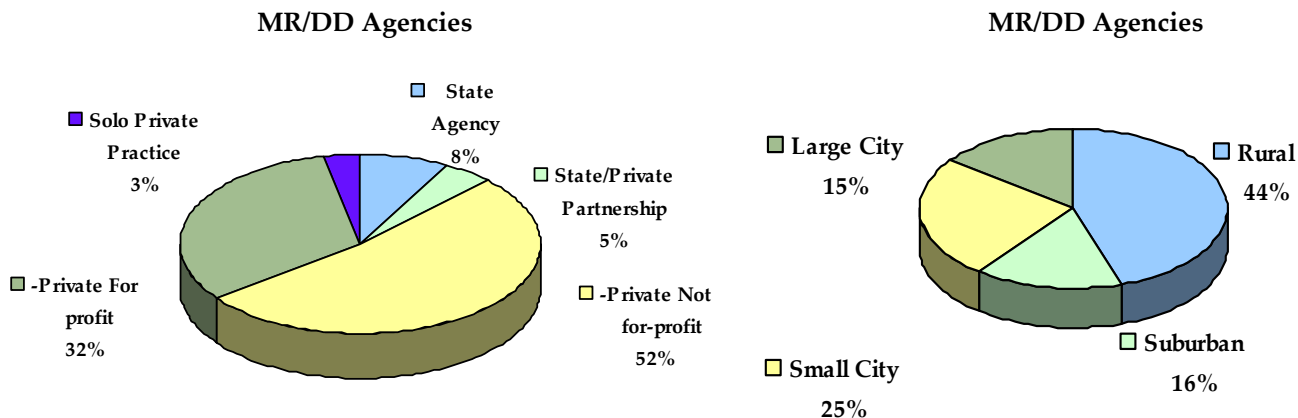
as “very effective” on average, strongly suggesting that other MR/DD agencies may also benefit from the use of these EBPs.

MR/DD Survey Response

Of the 808 MR/DD agencies asked to participate in the survey, 124 unique agencies responded, a response rate of 15%. Only surveys that were more than 25% complete were included in our analyses, resulting in completed surveys from 111 unique agencies, 14% of all MR/DD agencies contacted to participate. Of the 111 completed agency surveys, 18% reported that they served mental illness in addition to mental retardation/developmental disabilities, and 18% served both substance use disorders and mental illness in addition to mental retardation/developmental disabilities.

MR/DD Agency Type, Availability, and Geographic Area Served

Agencies were asked basic questions regarding the type of agency they consider themselves, their appointment availability, and the geographic areas they serve (see results below). About half of the agencies (52%) were private not-for-profit agencies. Almost half serve rural (44%) areas, and surprisingly few cities and suburban areas. It is unclear whether this is due to a concentration of DMH contracted MR/DD agencies in rural areas or a response bias that resulted in a stronger response from rural areas. It may also be that there are fewer, larger facilities in urban areas, and a larger quantity of smaller, independent agencies in rural areas. A large majority of agencies reported offering evening (80%) or weekend (75%) appointments.



MR/DD Agency Characteristics

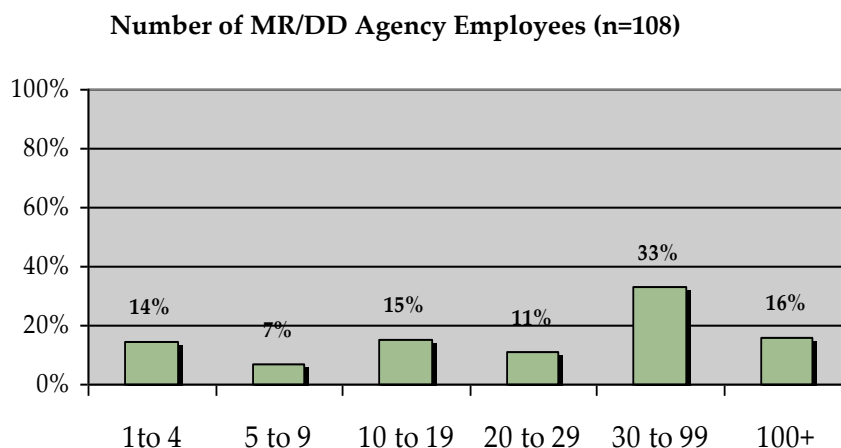
Agencies were also given a list of classifications and asked to check all that apply to them. About a third of the agencies were group homes, independent supported living (ISL), and/or offered community support. Approximately 14% of the MR/DD sample offered case management. Respondents were also asked to list any classifications that were not on the list. Commonly stated classifications included day

habilitation programs (12 agencies), recreation services (5 agencies), supported employment (5 agencies), transportation (4 agencies), Senate Bill 40 Board (4 agencies), foster home (3 agencies), and respite (3 agencies).

MR/DD Agency Workforce

About half of MR/DD agencies surveyed were medium or large sized agencies. As is shown below, 49% had 30 or more employees. The majority (51%) were small to medium sized agencies, with 14% having 1 to 4 employees.

The agencies were also asked what types of employees they had in-house to provide services. Of the 111 agencies, very few had psychiatrists (less than 1% employed at least one in-house), nurse practitioners (less than 1%), physicians (less than 1%), psychologists (2%), certified substance abuse counselors (2.7%), vocational/educational counselors (4.5%) or licensed professional counselors (5.4%). The majority of employees were registered nurses (57% employed at least one in-house), case managers (28%), licensed practical nurses (22%), paraprofessionals (19%), or social workers (14%).

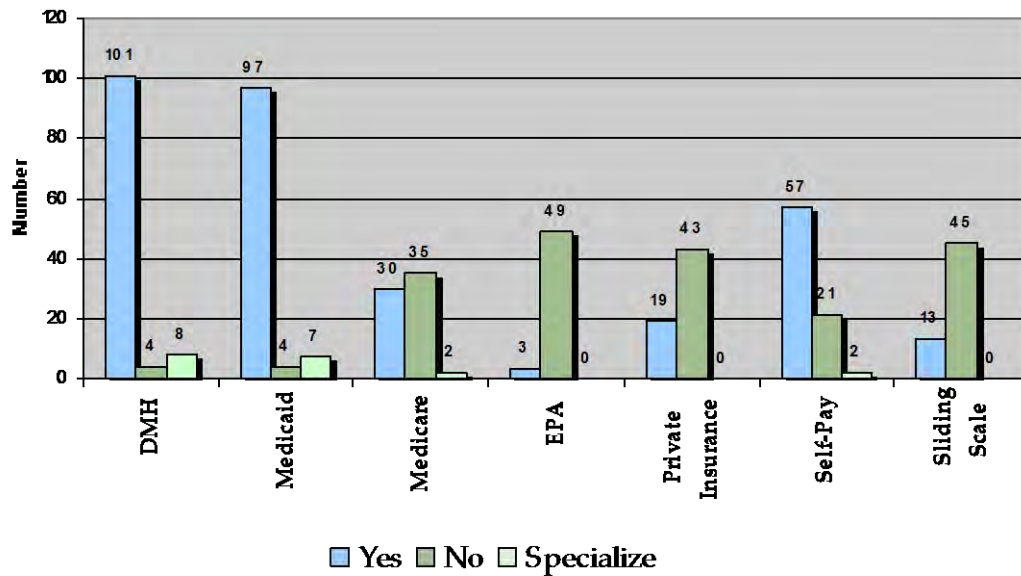


In general, contracting for professionals was not a popular practice among MR/DD providers. The most common professionals were registered nurses (23% agencies contracted with at least one) and case managers (12%). It was more common for MR/DD agencies to contract with professionals such as physicians (12% contracted with at least one), psychiatrists (11%), psychologists (7%), licensed professional counselors (6%), and nurse practitioners (6%) than to employ them in house.

MR/DD Agency Sources of Consumer Funding

Agencies were asked to choose the sources from which their consumers pay for services. If they specialized in a consumer receiving a certain type of funding, they were also asked to choose the "Specialize" box. Almost all agencies reported that their consumers receive funding from DMH (101 agencies, 91% of all agencies), an unsurprising finding given that the agencies were chosen from a list of DMH contracted providers. Self-pay and sliding scale payments were also commonly reported sources of funding. Other common sources of funding included tax levies (8), SB40 boards (5), and DESE (7).

MR/DD Sources of Client Funding (n=111)



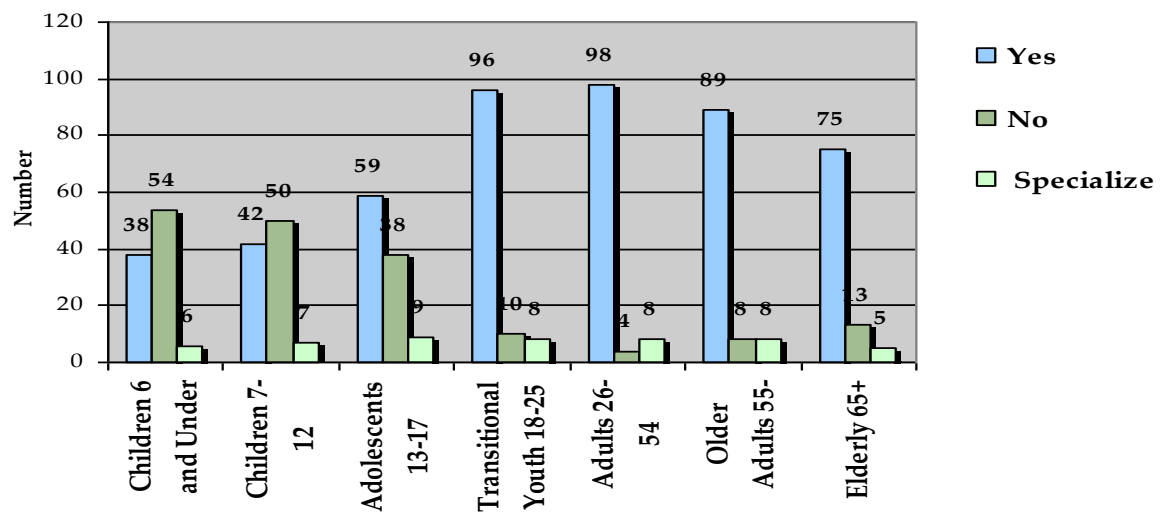
MR/DD Agency Consumer Characteristics

Agencies were asked various questions with the goal of understanding the populations they serve. Agencies were not only asked whether they served consumers with particular characteristics, but they were also asked to check “Specialize” if they specialized in serving that type of consumer.

Demographic Characteristics

The ages served by the agencies are shown in the figure below. Almost all agencies served adults, and approximately half served children and adolescents. The least commonly served group was children under the age of six years, followed closely by those aged 7-12. The most common age specialization was adolescents aged 13-17. Almost all agencies served adults, both younger adults (e.g., transitional youth) and older adults (aged 55-64), although fewer served the elderly. Agencies were also asked what genders they served. Almost all agencies served both males and females; six agencies specialized in serving females and five specialized in males.

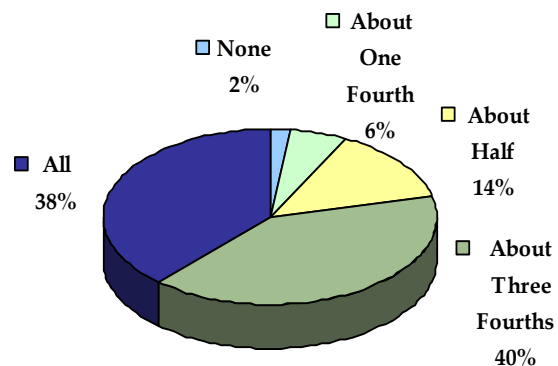
Ages Served by MR/DD Agencies (n=111)



Cultural Characteristics

We were interested in knowing not only the cultural characteristics of the population, but also to what extent the treatment staff shares the cultural background of the treatment population. “Cultural” was broadly defined as ethnicity, gender, age, and sexual orientation. Approximately 85% of agencies reported that Caucasian clients make up more than 20% of their clientele. About a third reported that African-American individuals were more than one fifth of their clientele, and 8% reported that Hispanics consisted of more than 20% of their clientele. In terms of treatment staff, the pie chart below shows that a large majority of agencies (78%) reported that around 75% or more of their treatment staff shares the cultural background of the individuals seeking treatment. Only 8% of agencies reported that around 25% or less of their treatment staff shares the cultural background of the clientele.

Percent of MR/DD Treatment Staff that Shares Cultural Background of Clientele (n=107)

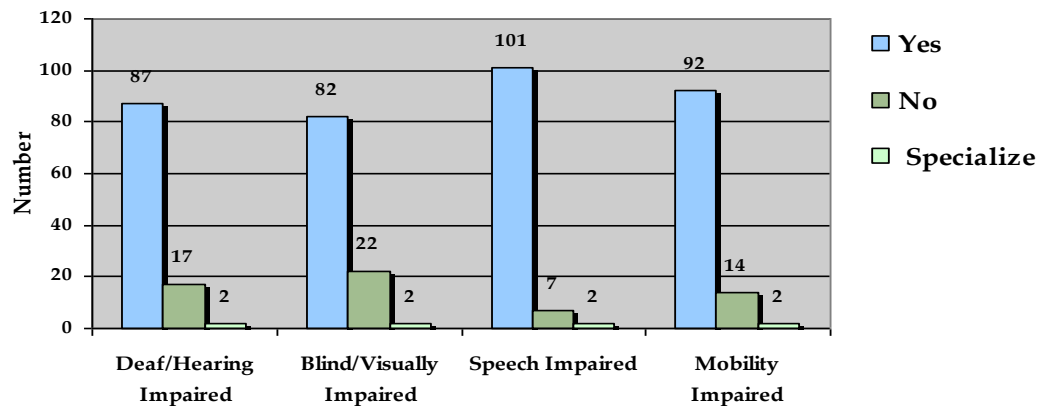


Agencies were also asked about the languages their programs can support. The most commonly supported languages were American Sign Language (9 agencies) and Spanish (5 agencies). German, French, & Bosnian were each supported by one agency. Five agencies reported that they can support any language through contracted interpreters.

Physical/Sensory Impairment

MR/DD agencies were asked if they serve individuals with specific impairments, and if they specialize in serving any particular population with various sensory and physical impairments. Results (see chart below) indicate that almost all MR/DD agencies serve individuals with various impairments. Fewer report specializing in serving those populations.

MR/DD Agencies that Clients with Physical or Sensory Impairments (n=111)

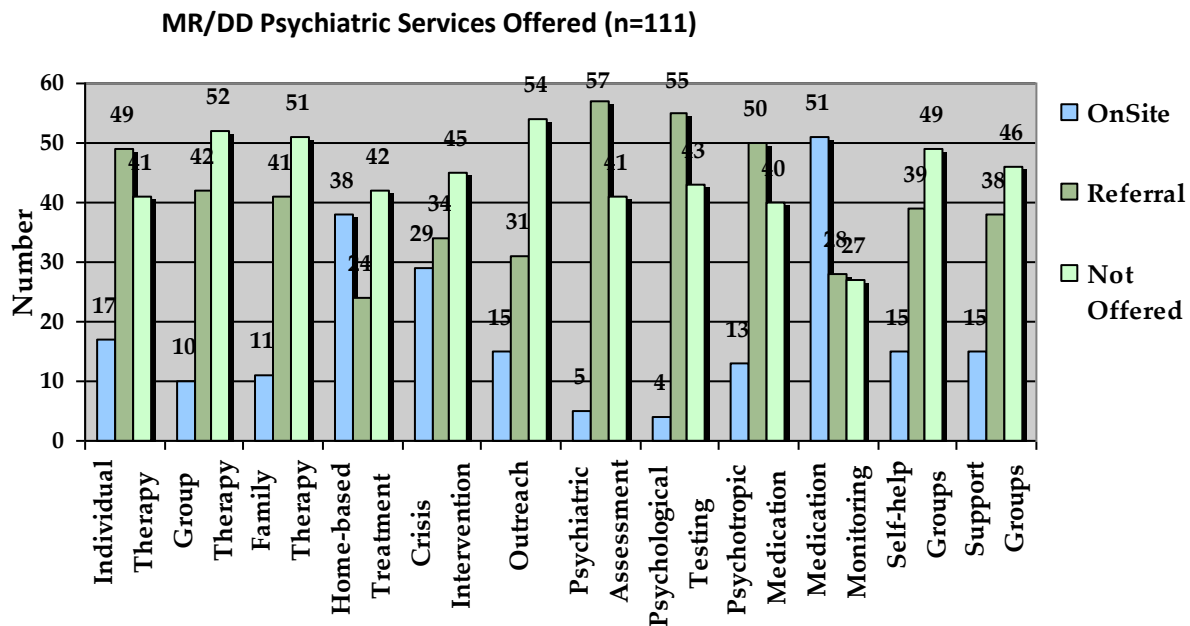


MR/DD Agency Services Offered

Agencies were given a long list of services, and asked which ones they offer on-site and by referral. For purposes of this report, services are divided into several categories: Psychological Services, Addiction/Substance Abuse Services, Educational and Vocational Services, Medical Services, Social Services, Prevention Services, and Other Support Services.

Psychiatric Services

Of the 111 MR/DD agencies surveyed, the most commonly offered service on-site was medication monitoring (46%), followed by home-based treatment (34%). Individual therapy, psychiatric assessment, psychological testing, and psychotropic medication were commonly offered through referral. About half of the sites could offer most services through referral. Outreach, family therapy, and group therapy were the least often offered services.



Addiction/Substance Abuse Services

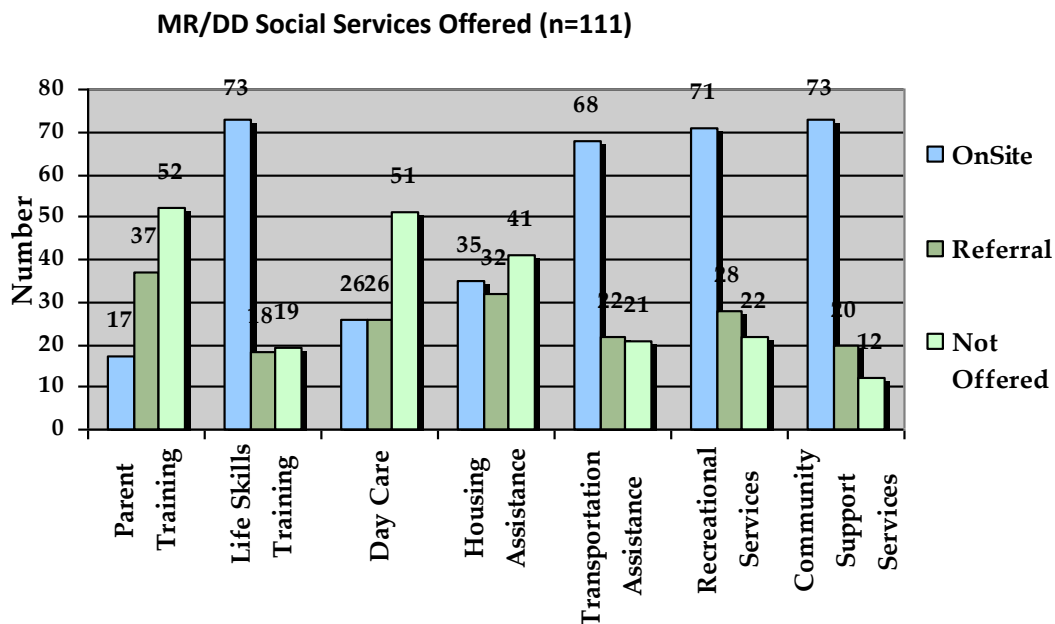
Substance abuse screening and other addiction services were generally not offered on-site. About one-third to one-half of sites could give referrals if needed.

Educational and Vocational Services

Sheltered workshops, supervised on-site job placement, and job placement were offered either on-site or through referral by the majority (about two-thirds) of MR/DD agencies. Tutoring/homework assistance and supervised on-site job placement services were the most commonly offered on-site educational and vocational services (offered on-site by about 20% of agencies), although tutoring/homework assistance was not commonly available through referral if it was not offered on-site (only a quarter of sites offered it through referral). Overall, special education, GED/college preparation, and tutoring/homework assistance were the least commonly available services, with about half of MR/DD agencies not offering those services on-site or through referral.

Social Services

Social services were among the most common on-site services offered, with the majority of sites offering life skills training, recreational services, transportation services, and community support services on-site. Housing assistance was offered on-site by less than one-third of all sites. Day care and parent training were offered least.



Prevention Services

It was common for sites to offer social skills training, with more than two-thirds (n=76, 68%) offering it on-site. About a third of sites offered other kinds of prevention services either on-site or, more commonly, through referral.

Medical Services

Sites were asked what kind of medical services they offered to their clients. Approximately 7% of sites (8) offered on-site medical exams upon admission, 44% (50 sites) upon referral, and 44% (50) did not offer them at all. Seven sites (6%) offered an annual medical exam on-site, 54 (47%) offered them on referral, and 48 (42%) did not offer them at all.

Other Support Services

Fifteen sites (13%) offered psychosocial rehabilitation on-site and 39 (34%) offered it through referral. Benefit acquisition assistance was offered on-site by 16 (14%) sites, school-based services were offered by 8 (7%) sites, children services were offered on-site by 16 (14%) sites, faith-based services were offered by 16 (14%) sites, and legal services were offered on-site by three (2.6%) sites (1 offered legal service counseling and 3 offered legal advocacy).

Sites were also asked to list any services they offer that were not on the list. MR/DD agencies offer a wide array of services to those with mental retardation and developmental disabilities. Commonly listed services offered included the following: independent supported living (ISL), residential rehabilitation,

day habilitation, respite, recreation, community integration, personal care assistance, and 24-hour nursing care.

MR/DD Ranking of Needs

Ranking of Needs of Individuals with Mental Retardation/Developmental Disabilities

MR/DD agencies were asked what they felt were the strongest needs of individuals with mental retardation and developmental disabilities. See the table on page 17 for a list of all needs and their calculated strength. “Strength of Need” was determined through response options on a Likert Scale, where 1 = “No need at all” and 4 = “Critical need.” The mean of all respondents’ answers was taken to get the strength of need for that question. Respondents had a tendency to rate all needs as “High Need” so the strength of the need was calculated so that the needs could be ranked.

The top ranked needs were:

- Shorter waiting lists for housing.
- Behavior management services (tied with #3).
- Affordable housing (tied with #2).
- More convenient transportation. (tied with #5 and #6)
- Handicapped accessible housing. (tied with #4 and #6)
- More employment opportunities. (tied with #4 and #5)
- Better paying employment opportunities.
- More affordable transportation.
- Handicapped accessible public transportation.
- More employment supports.

The list primarily includes needs for affordable, handicapped accessible housing and transportation, behavior management services, and an increase in better paying employment opportunities. Respondents also had an opportunity to list other needs if they didn’t see it on our list. The most commonly listed other needs included dental services, consistency between regional centers, and more housing choices.

MR/DD Providers Ratings of Needs (n=111)

	No Need At All	Low Need	High Need	Critical Need	Don't Know	Strength of Need (1-4 Scale)
<i>General Needs</i>						
Public MR/DD education/awareness	0.9%	21.3%	55.6%	17.6%	4.6%	2.96
Adult day programming services	3.7%	19.3%	46.8%	23.9%	6.4%	2.97
Early intervention services	4.7%	11.3%	52.8%	15.1%	16.0%	2.93
Employment support	2.8%	17.6%	52.8%	21.3%	5.6%	2.98
Individualized education supports	1.9%	19.6%	53.3%	11.2%	14.0%	2.85
Available/affordable recreation activities	2.7%	20.7%	53.2%	18.9%	4.5%	2.94
Available/affordable physical care	3.8%	24.5%	47.2%	17.9%	3.8%	3.00
Case Management	10.4%	31.1%	44.3%	8.5%	5.7%	2.55
Counseling Services	5.7%	23.6%	44.3%	16.0%	10.4%	2.81
Qualified MR/DD service providers	5.6%	29.0%	40.2%	19.6%	5.6%	2.76
Additional MR/DD providers/staff/sites	8.7%	28.8%	33.7%	19.6%	5.6%	2.70
<i>Access Needs</i>						
Affordable transportation	1.8%	22.0%	37.6%	32.1%	6.4%	3.09
More convenient transportation services	2.8%	17.4%	36.7%	34.9%	8.3%	3.14
Handicapped accessible public transportation	1.9%	21.5%	36.4%	30.8%	9.3%	3.08
<i>Child Care Needs</i>						
More childcare options	6.6%	16.0%	33.0%	12.3%	32.1%	2.77
Affordable childcare	6.6%	8.5%	34.0%	19.8%	31.1%	3.00
Qualified childcare providers	3.8%	15.1%	33.0%	15.1%	33.0%	2.91
<i>Family Mental Health Needs</i>						
In-home supports and services	2.7%	23.6%	47.3%	21.8%	4.5%	2.93
Respite care	2.7%	21.8%	44.5%	23.6%	7.3%	2.97
Behavior Management Services	1.8%	12.8%	45.0%	32.1%	8.3%	3.17
Family Support Groups	2.8%	25.7%	41.3%	11.0%	19.3%	2.77
<i>Housing Needs</i>						
Safe housing	5.5%	20.0%	44.5%	18.2%	11.8%	2.87
Affordable housing	3.6%	11.8%	44.5%	32.7%	7.3%	3.17
Handicapped accessible housing	1.8%	13.6%	49.1%	29.1%	6.4%	3.14
Shorter waiting lists for housing	1.9%	12.0%	40.7%	34.3%	11.1%	3.23
<i>Employment Needs</i>						
More employment opportunities	2.8%	10.1%	51.4%	27.5%	8.3%	3.14
Better paying employment opportunities	1.9%	13.9%	50.9%	26.9%	6.5%	3.11
Decreased employer stigma	2.9%	19.6%	39.2%	23.5%	14.7%	3.01
Sheltered workshops	12.1%	30.8%	32.7%	15.0%	9.3%	2.56
Vocational training	1.9%	17.9%	51.9%	18.9%	9.4%	2.97
More employment supports	2.8%	13.2%	47.2%	25.5%	11.3%	3.07

If you were to advocate for one change to the mental health care system, what would it be?

In order to further assess the needs of MR/DD agencies, respondents were asked to describe what change they would advocate for if they could only choose one issue. One hundred thirty-five individuals responded to the question. Analysis of the responses indicates that they revolved around several key issues.

"My group home is very under funded and is still based on a e0 year old rate system...[it] is not funded for [the] service it is expected to provide. This home has 5 consumers that have lived here for over 30 years."

-- MR/DD Agency Respondent

Funding for Services

The number one change requested by respondents (23 individuals) was to increase the funding for individuals with mental retardation/developmental disabilities and those with mental health issues so that additional services could be offered and more individuals

could be served. Some suggestions for the extra funding included providing money for recreation, quality day programs and workshops, and assistance with daily skills. Respondents also suggested more MO HealthNet funding for psychiatrists, doctors, and dentists. One individual suggested better allocation of the Division of Comprehensive Psychiatric Services (CPS) funding for services other than those offered through the Community Psychiatric Rehabilitation (CPR) program, "since that program is not the solution for every mental health program." Another individual suggested low cost mental health services for those who could not reach the closest CPS provider.

Better Coordination and Consistency of Services

Twenty-one respondents listed a number of issues affecting the coordination between systems and resultant lack of consistency of services across services within DMH. Agencies emphasized a need for a better relationship between DMH and community providers. Different paperwork and procedures between regional centers, as well as lack of clarity regarding regulations and expectations were very commonly listed concerns. Providers were also concerned about a change in case management services. A couple individuals suggested keeping the service coordinator in place at the Regional Centers. Finally, one agency felt that that "fee for service" reimbursement required a "constant balancing act on the part of providers to meet budget" which made it difficult to provide a consistent quality services.

The difficulty in serving mental retardation/developmental disabilities individuals with co-occurring disorders, and the need to coordinate services for these individuals, was also mentioned by several respondents. One respondent felt there needed to be a "better partner relationship...less negative, punitive role" for MR/DD within DMH. More assistance from mental health providers for individuals with mental retardation/developmental disabilities in crisis was also a stated concern.

Consumer-driven Care

"I have seen the system fail individuals and their situations because power/pride from the Regional Center got in the way of doing what was truly best for the individual...many desperate situations are created because consumers are waiting for a decision from the Regional Center."

-- MR/DD Agency Respondent

Related to the relationship between DMH and community providers was the feeling of several agency respondents that bureaucracy sometimes got into the way of providing quality consumer-driven care. Some respondents felt that services were driven more by the DMH budget rather than what was best for consumers. One individual felt that the "maze of bureaucracy" should be replaced with "one stop shopping."

Better Pay for Providers/Staff

A number of respondents (10) felt that the key to improving the system lies in paying competitive wages in order to retain competent, well-trained staff. Agency respondents felt the only way to ensure high quality, dedicated staff, was to pay them commensurate to similar staff working in the for-profit sector. There was recognition among agency respondents that the responsibilities and difficulties of providing direct personal care to individuals with mental retardation/developmental disabilities and mental illness often outweigh the wages currently offered to staff.

Community Support Services

Many agency respondents (10) felt that there were not enough community based resources to help individuals with mental retardation/developmental disabilities become independent members of the community. Respondents gave several examples of why more services are needed, from a rural individual who does lives too far from a sheltered workshop, to a person with MR/DD and co-occurring disorders who does not have the transitional services needed to move from institutional to independent living. Respondents mentioned needs for better transportation, more education and employment opportunities, help with daily skills, and more funding for recreational activities. One respondent suggested that programs incorporate a "safe way to experience actual consequences" so that individuals with mental retardation/developmental disabilities are better prepared for entering the community.

"Unfortunately, there are people who work in fast food who make as much as our employees do."

-- MR/DD Agency Respondent

Psychiatric Care/Psychiatrists

The lack of psychiatric services for individuals with mental retardation/developmental disabilities and mental illness were among respondents' concerns. Many comments were related to the lack of coordination between different agencies within DMH, as well the difficulties of accessing psychiatric services in rural areas. One individual suggested an increased capacity of short-term in-patient beds and mental health services for individuals with mental retardation/developmental disabilities.

Other Suggestions

There were a number of other suggestions given by MR/DD agency respondents that did not fall into the above categories. Among those, the most common were a desire to localize and privatize services and a need for more training of staff. A few respondents felt that more autonomy on a local level and some privatization would allow for more consumer choice. Training issues were noted, included comments from several respondents indicating that staff needed training on how to deal with difficult situations encountered while serving individuals, and that case managers also needed more training. A few individuals also mentioned a need for more family support services, including respite care and help dealing with behavior difficulties.

"Privatizing some of the services offered by the state would free up money to provide more service or enhance existing services."

-- MR/DD Agency Respondent

Effectiveness and Use of Evidence-based Practices by MR/DD Agencies

All agencies were asked if they used EBPs in their facilities. Of the 98 MR/DD agencies that responded to the question, 56% reported that they use EBPs (for a total of 55 agencies that use EBPs). Agencies were also asked whether they use various selected EBPs, and if so, to rate their effectiveness. The list of EBPs, along with the ratings, is shown below. The list of EBPs was based on a list developed by Washington State, and modified by researchers at the Missouri Institute of Mental Health (MIMH) with assistance from DMH. MIMH researchers reviewed prevention literature and added various prevention EBPs not on the original list. In addition, EBPs of interest to DMH were added.

The table below shows all EBPs used by five or more agencies, and their ratings. Of the 47 EBPs from which agencies could choose, five or more agencies used 23 (49%) of the EBPs listed. As shown in the table, the most commonly used EBPs were Positive Behavior Supports (n=49, 89% of agencies who reporting), Person Centered Planning (n=47, 85%), Life Skills Training (n=33, 60%), and Medication Management (n=27, 49%). As can also be seen in the table, each EBP was also given a number meant to indicate its "Effectiveness" as judged by agency respondents. Effectiveness was determined by putting the response options on a Scale of 1 to 4, where 1 = "A little effective" and 4 = "Extremely effective." The mean of all respondents' answers was taken to get the overall effectiveness for that EBP. The resulting number allowed us to determine which EBPs were rated as most and least effective by the agencies that use them. A number of EBPs were used by very few agencies, so their ratings may be a less reliable

indicator of effectiveness in MR/DD agencies than those with more agencies using them. Furthermore, the fact that an EBP is used by a large number of agencies may, in some cases, be a testament to its success with the MR/DD population. In fact, the two most commonly used EBPs, Positive Behavior Supports and Person Centered Planning, were among the highest rated EBPs as well. Both were rated “very effective” overall by the agencies that used them.

Effectiveness and Use of Selected Evidenced Based Practices by MR/DD Agencies (n=55)

	Number who reported offering EBP	A Little Effective	Somewhat Effective	Very Effective	Extremely Effective
Dialectical Behavioral Therapy (DBT)	5	20.0%	20.0%	60.0%	0.0%
Peer Support	10	10.0%	30.0%	40.0%	20.0%
Person Centered Planning (PCP)	47	2.1%	23.4%	48.9%	25.5%
Positive Behavior Supports	49	0.0%	26.5%	49.0%	24.5%
Sharing our Strengths	10	30.0%	20.0%	20.0%	30.0%

CHAPTER EIGHT

MISSOURI MENTAL HEALTH SERVICES AND RESOURCES

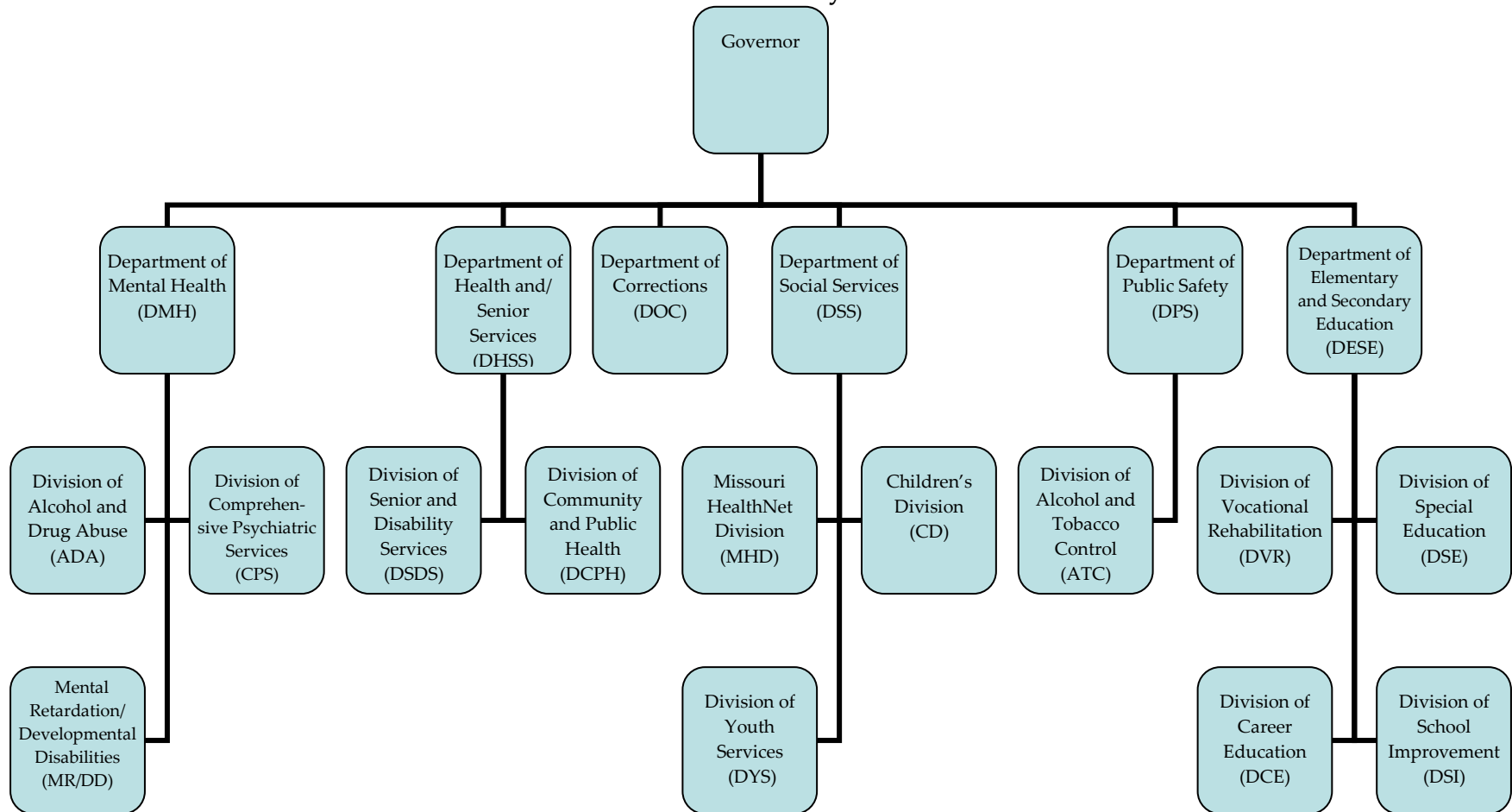
Introduction

This chapter of the Needs Assessment and Research Inventory (NARI) describes the resources offered by state departments for addressing mental health treatment needs. The chapter aims to both describe these services and identify collaborative efforts and levels of fragmentation that exist between state departments.

State-funded mental health services in Missouri are funded primarily through the Missouri Department of Mental Health (DMH) and the Missouri HealthNet Division (formerly the Medicaid Division) within the Department of Social Services (DSS). Within DMH, three divisions serve the mental health needs of the state: the Division of Comprehensive Psychiatric Services (CPS), serving those with psychiatric disorders, the Division of Alcohol and Drug Abuse (ADA), providing substance abuse treatment and prevention services, and the Division of Mental Retardation/Developmental Disabilities (MR/DD), assisting those with mental retardation and developmental disabilities. The Missouri HealthNet Division purchases and monitors health care services for low income and vulnerable citizens of the State of Missouri (Medicaid and MC Plus).

In addition to DMH and the MO HealthNet Division of DSS, several other departments also provide treatment services or contract with CPS for care. These include the Department of Corrections (DOC), the Department of Elementary and Secondary Education (DESE), two additional divisions within DSS, the Department of Health and Senior Services (DHSS), the Department of Public Safety (DPS) and the Office of State Courts Administrator. The organizational chart below illustrates the state departments involved in the delivery of mental health care services in Missouri. This chapter contains a list of specific state and consumer services and resources, and technological resources.

State Mental Health Service System Structure²⁰



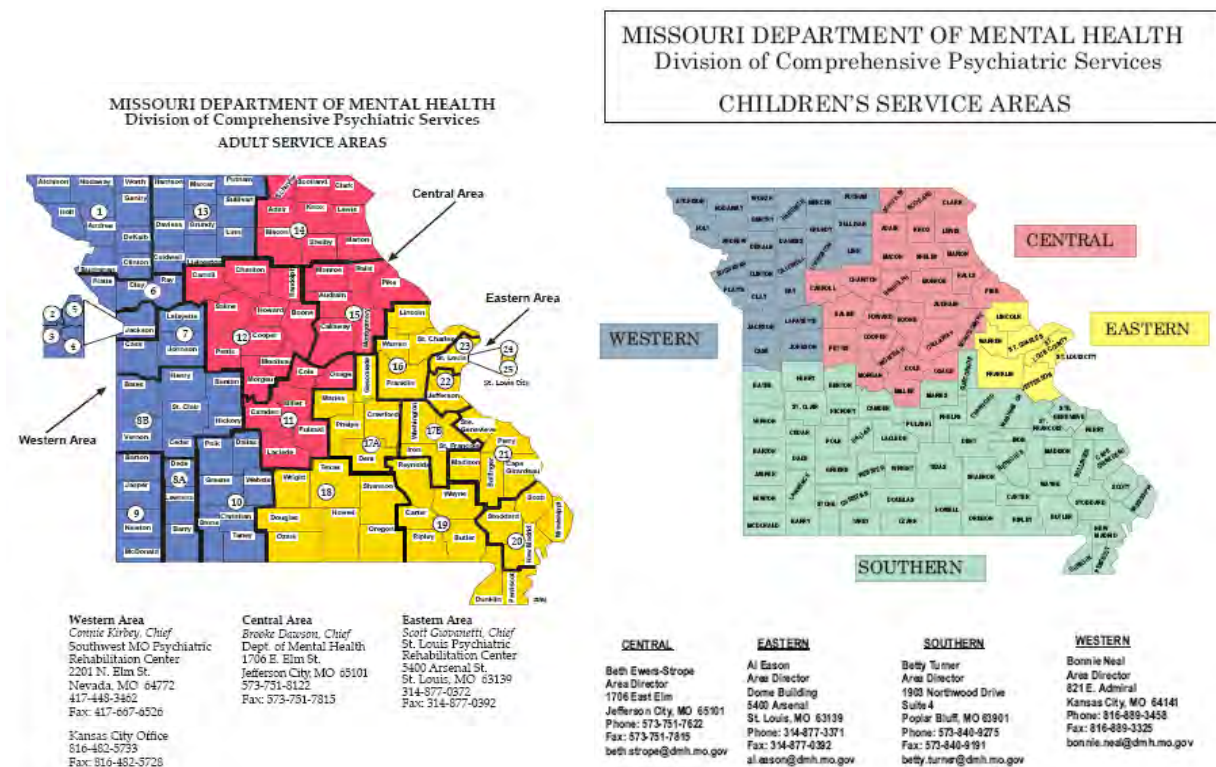
²⁰ The Office of State Courts Administrator is involved in mental health care through its mental health courts. This office reports to the Supreme Court.

Missouri Department of Mental Health

As the primary department responsible for mental health care service delivery, DMH provides services for those with psychiatric, substance abuse and gambling disorders, and mental retardation and developmental disabilities. Psychiatric services are offered through CPS. Substance abuse and gambling services are offered through ADA. Services for those with mental retardation and developmental disabilities are offered through MR/DD. DMH services are funded through a variety of sources such as: MO HealthNet, general revenue allocated by the state, federal grants, insurance, and self-pay determined by the Missouri state sliding scale. The state receives a 62% federal match for all MO HealthNet (formerly Medicaid) recipients.

Division of Comprehensive Psychiatric Services (CPS)

CPS provides mental health treatment and recovery services for persons with mental illness. In-patient care is offered at eleven division-operated facilities that provide acute, long term rehabilitation, and residential care for youth and adults; as well as forensic, sexual predator and corrections services for adults. Out-patient services are contracted out to provider agencies across the state. The maps below indicate the service areas for adult and children's services throughout the state.



Eligibility Criteria

CPS is committed to serving four target populations: persons with serious and persistent mental illness (SMI); persons suffering from acute psychiatric conditions; children and youth with serious emotional disturbances (SED) and forensic clients. In addition, CPS has identified four priority groups within the target groups; (1) individuals in crisis, (2) people who are homeless, (3) those recently discharged from in-patient care and (4) substantial users of public funds. These target populations currently constitute the majority of consumers whom the Division serves both in in-patient and ambulatory settings.

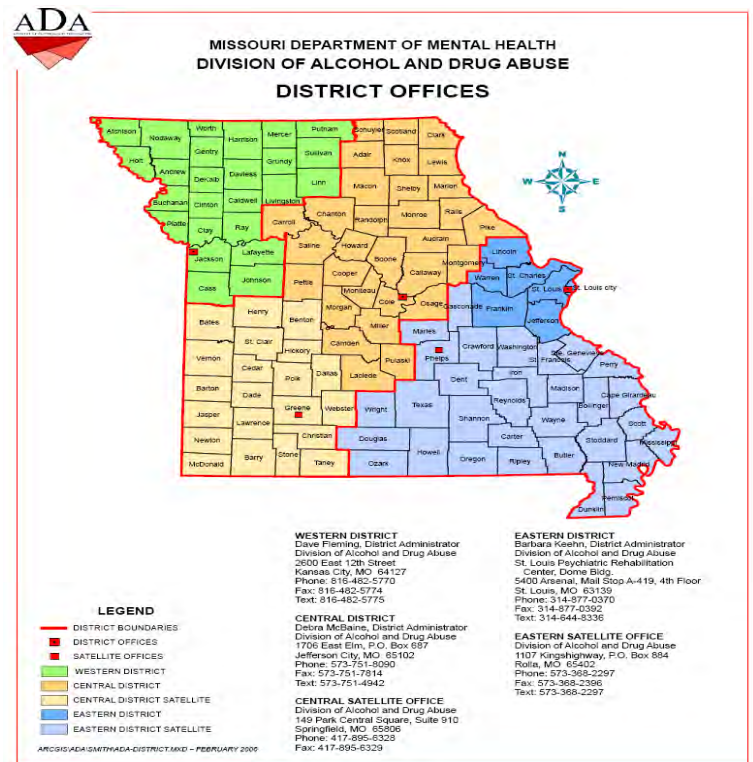
CPS Programs and Services

Program or Service	Description
In-patient long term psychiatric care (adults)	Four facilities in eastern, western, central and southeast Missouri; one long-term facility for sexual offenders in southeast Missouri.
In-patient acute psychiatric care (adults)	Four hospitals located in eastern, western, central and southeast Missouri.
Children's in-patient psychiatric and residential treatment	<ol style="list-style-type: none">1. One residential facility for children aged 6-17 who have severe emotional disturbance, as well as those children dually diagnosed with emotional disturbance and mental retardation.2. One facility with in-patient, residential and day treatment care.
Out-patient psychiatric services (adults and children)	25 community mental health centers (CMHCs) and their affiliates. Services include screening, assessment, individual treatment plan development, crisis intervention, case management, medication management and community support.
Day Treatment/Partial Hospitalization	Services may include vocational education, rehabilitation services, and educational services. The focus is on developing supportive medical, psychological and social work services.
Respite Care	Temporary care given to individuals by specialized, trained providers for the purpose of providing a period of relief to the primary care givers.
Community Psychiatric Rehabilitation (CPR) services	The Community Psychiatric Rehabilitation Program offers services to Medicaid-eligible persons living in the community with severe, disabling mental illnesses. Services include evaluations, crisis intervention, community support, medication management, and psychosocial rehabilitation.
Community placement	The Supported Community Living program offers community placement in nursing homes, apartments and other standard living arrangements in the community. Persons receive case management and support through Community Psychiatric Rehabilitation Programs.

Program or Service	Description
Licensed treatment family homes	Private family residences licensed to provide specialized, 24-hour support, case management, and out-of-home care for youths with Serious Emotional Disturbances.
Crisis Services	<p>Hotlines: CPS funds 10 mental health care Access Crisis Intervention (ACI) hotlines. These hotlines operate 24 hours a day every day.</p> <p>Crisis training: Law enforcement officers are trained to better respond to persons in crisis due to mental illness and to get them to treatment.</p>
Disaster Services	The Office of Disaster Readiness (ODR) conducts planning and development activities to support a coordinated mental health response for Missourians in disaster situations. This includes preparedness training in psychological first aid.
Trauma services	Policy statement regarding trauma including identifying general and trauma informed competencies. Trauma training in children's residential facilities, annual trauma training, and trauma training for returning veterans with PTSD; Trauma Screening Program for Children training; training on Trauma Focused Cognitive Behavioral Therapy.
Services for the homeless	The Projects for Assistance in Transition from Homelessness (PATH) Program supports service delivery to individuals with serious mental illnesses, as well as individuals with co-occurring substance use disorders, who are homeless or at risk of becoming homeless. There are eleven PATH programs across Missouri in both rural and urban areas.
Rental assistance for homeless and disabled (with ADA and MR/DD)	Rental assistance provided through Shelter Plus Care (SPC), a HUD-funded rental assistance program that brings together housing and mental health services.
Employment assistance for persons with mental illness and co-occurring disorders	Several evidence-based programs including (1) Supported Employment (SE) (job coaches, transportation, assistive technology, specialized job training, and individually tailored supervision); (2) Integrated Dual Diagnosis and Treatment (IDDT) for individuals with co-occurring disorders, which requires a vocational specialist; and (3) Assertive Community Treatment (ACT) requires a vocational specialist and it will be implemented at six Community Mental Health Centers in 2008. (with DESE's Division of Vocational Rehabilitation)
Alternatives to restraint and seclusion	Fulton State Hospital is using a restraint and seclusion training curriculum developed by National Association of State Mental Health Program Directors (NASMHPD) to train staff within the intermediate and maximum-security forensic units. All facility staff has completed this training program, and other facility administrators and managers across the state are being trained through this facility as well.

Division of Alcohol and Drug Abuse (ADA)

ADA is responsible for making prevention and treatment services accessible to persons with substance abuse disorders, to those at risk of substance abuse, and to problem gamblers. Services are provided through a statewide network of contracted community agencies that provide substance abuse prevention and treatment, recovery supports, compulsive gambling and the substance abuse traffic offender program. The Division directly operates one small outpatient clinic. The map of District Offices identifies the counties in each District and contacts for each region of the state.



ADA Programs and Services

Program or Service	Description
Community 2000	Community 2000 is a network of 150 volunteer community teams focusing on reducing the incidence of substance use and abuse in their communities and changing community norms toward substance use by youth and others.
Regional Support Centers	Regional Support Centers are the primary source of technical assistance support for the Community 2000 Teams. Each center has a prevention specialist who works directly with the teams to assist with development of teams and task forces in communities. The center plays a key role in Missouri's efforts to limit the sale of tobacco products to underage youth.
School-based Initiative (Missouri SPIRIT)	SPIRIT supports the development and implementation of a continuum of substance abuse prevention services in five public schools in Missouri.
Community-Based Services	Community-based prevention services for youth are offered by community agencies utilizing science-based programs. These programs target youth at high risk of early use of alcohol and other drugs.

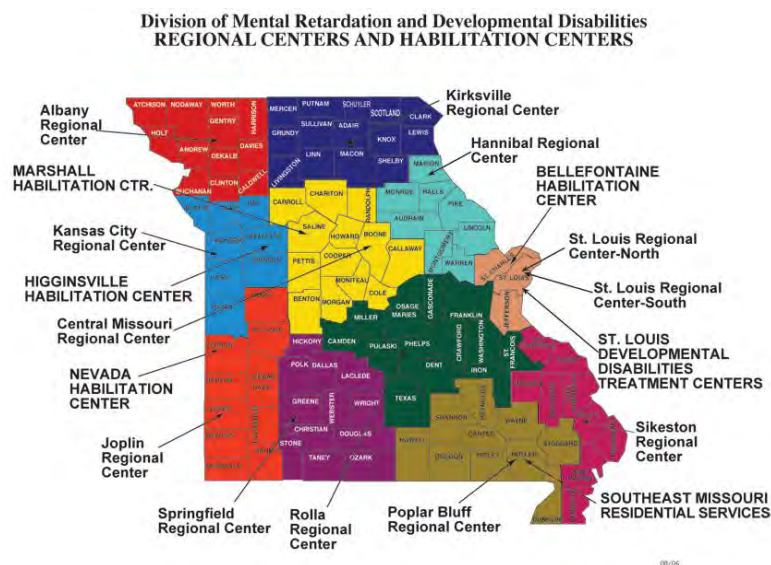
Program or Service	Description
Statewide Training and Resource Center	This center provides resources, training, and technical assistance to Regional Support Centers and community-based providers. Prevention conferences and workshops are provided by the center. The center operates the Community 2000 mini-grant program and the statewide Regional Alcohol and Drug Abuse Resource network (RADAR) resource site.
Comprehensive Substance Treatment and Rehabilitation (CSTAR) Programs <ul style="list-style-type: none"> • Women and Children's Programs • Adolescent Programs • General Population Programs • Opioid Programs 	Substance abuse services are provided in a community-based setting by contracted providers. The intensity of services is based upon a consumer's assessed needs and provided on a continuum from daily treatment with residential support to monthly outpatient sessions. Services are available to both the consumer and their families. If the consumer is Medicaid eligible services are funded through the state and MoHealthNet.
Primary Recovery Plus Programs/Enhanced Primary Recovery Plus Programs	Comprehensive substance abuse treatment services are provided through contracted treatment providers. Services include social setting detoxification and intensive treatment including supportive housing when needed. A primary focus is provision of a complete continuum of recovery services including intensive outpatient and supported recovery levels of care. Enhanced programs offer modified medical detoxification services by medical personnel.
Recovery Support Services	Recovery support services are a complementary array of activities, resources, and services designed to assist an individual's integration into the community, participation in treatment, improved functioning and recovery. The services are provided by trained clergy, ministers, mentors, and lay people who have experience in addiction recovery. These supports provided by community- and faith-based organizations introduce a person to recovery and offer long term connectedness.
Compulsive Gambling Counseling	Treatment for problem gambling is provided through a network of contracted treatment providers by specially trained and certified counselors. Individuals with gambling problems and their families can receive free counseling services along with referrals for other supportive interventions.
Substance Abuse Traffic Offender Program (SATOP)	SATOP is Missouri's education and intervention program for drinking drivers. DWI offenders are required to complete this program for reinstatement of their driving privileges. The SATOP program provides screening for level of service, education programs, intervention programs and treatment.

Division of Mental Retardation and Developmental Disabilities (MR/DD)

MR/DD, established in 1974, serves a population that has developmental disabilities such as mental retardation, cerebral palsy, head injuries, autism, epilepsy, and certain learning disabilities. The Division, as outlined in 633.010 RSMo, is charged with the responsibility of insuring that mental retardation and developmental disabilities prevention, evaluation, care, habilitation and rehabilitation services are accessible, wherever possible. Furthermore, the division has supervisory responsibilities for division residential facilities, day programs and other specialized services operated by the department, and oversight over facilities, programs and services funded or licensed by the department. In 1988, the Division began participation in the Medicaid home and community-based waiver program, designed to help expand needed services throughout the state.

Mental health services offered to individuals with mental retardation or developmental disabilities are provided in most part by CPS division within DMH. Approximately 60% of all MR/DD clients were served by CPS in 2006.

Division of MR/DD Regional Centers and Habilitation Centers



Eligibility Criteria

Eligibility for MR/DD services is determined by a functional assessment as opposed to linking eligibility to a specific diagnosis. It must be determined that the mental retardation/developmental disability is likely to continue indefinitely and that it results in a substantial functional limitation in two or more of the following six areas of major life activities: self care, receptive and expressive language development and use, learning, self-direction, capacity for independent living or economic self sufficiency and mobility. All persons who are eligible for services receive service coordination services.

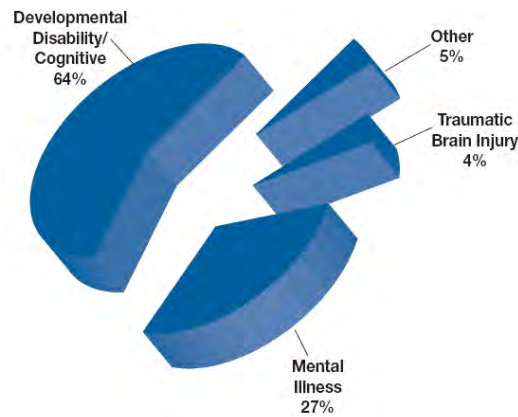
MR/DD Programs and Services

Program or Service	Description
Habilitation centers for persons with MR/DD	MR/DD operates six habilitation centers throughout the state which provide institutional care for persons with mental retardation or developmental disabilities. These centers offer training and habilitation for consumers unable to live in community settings because of the severity of their disabilities or for behavioral reasons.
Community MR/DD treatment services	MR/DD operates 17 entities that provide or purchase specialized services, assessment, and service coordination services, which include coordination of individual's person-centered plan. Eleven (11) are regional offices that provide service coordination and work with individuals, families and providers. Regional offices coordinate with Senate Bill 40 boards to assure service provision to MR/DD clients statewide.
Autism services	Five regional autism projects that collectively provide services to approximately 2500 families statewide. Individuals are referred to their autism projects through their regional office.
Transition services for MR/DD consumers	Using a variety of Medicaid waivers, MR/DD consumers are provided with transitional services to successfully transition from habilitation centers to the community. Services vary depending on the type of waiver, but can include personal assistance, behavior therapy, respite care, counseling, crisis intervention services, supported employment, individualized supported living and residential habilitation, counseling, and other needed support services.
Work incentives planning and assistance	<p>The Benefits Planning, Assistance and Outreach (BPAO) Program provides funding to community-based organizations, called BPAO Projects, to provide all SSA beneficiaries with disabilities access to work incentives planning and assistance services.</p> <p>The Ticket to Work and Work and Self Sufficiency Program provide access to employment training and placement services.</p>
Self-directed care	A consumer or family may choose to hire, train, supervise and schedule their own workers who are not licensed professionals. The consumer or family who chooses to direct their own personal assistant services becomes the employer of record for the workers they hire. The fiscal intermediary provides all necessary payroll functions for the employer of record (the consumer or family) and acts as a liaison with various regulatory and governmental agencies.

Department of Elementary and Secondary Education (DESE)

DESE is charged with providing elementary and secondary education in the State of Missouri. In the area of mental health, DESE provides funding for vocational rehabilitation within the Division of Vocational Rehabilitation (DVR) and these services are coordinated with the DMH. The figure to the right presents the breakdown of persons who exited DVR's Supported Employment program.

Diagnosis of Persons Exiting Supported Employment



DESE also provides services for those with developmental disabilities in the schools through the Division of Special Education (DSE). Services and programs related to mental health are listed below.

Department of Elementary and Secondary Education Programs and Services

Programs and Services	Description	Division
Vocational rehabilitation for persons with mental health disorders	Vocational Rehabilitation Counseling & Diagnostic Services	DVR
	Supported Employment provides employment supports in an integrated work setting in which individuals are working toward competitive employment. VR could provide up to nine months of community-based job training if other funding sources are available to provide long-term, follow-along, on-the-job support services that the individual needs to remain employed.	DVR
	Physical Restoration	DVR
	Training: Proprietary, Skills, Technical non-degree	DVR
	Training: College University	DVR
	Secondary Support Services (Transportation, Room & Board, etc.)	DVR
	Assistive Technology	DVR

Programs and Services	Description	Division
Special Education Services	For children with MR/DD, in response to the Individuals with Disabilities Education Act (IDEA), DESE coordinates with individual school districts to increase the number of persons able to serve students with disabilities, provide in-service training to staff, train paraprofessionals and disseminate information related to best practices, teaching approaches and other relevant information.	DSE
	DESE offers Positive Behavior Supports, a whole school evidence-based prevention and early intervention program across the state.	
Early childhood services	The First Steps program offers coordinated services and assistance to children from birth to age three who have delayed development or diagnosed conditions that are associated with developmental disabilities.	DSE
Elementary and secondary school social development and guidance	The Missouri Comprehensive Guidance Program (MCGP) is a program that teaches knowledge and skills that can instill in students the resilience and competencies to lead successful and healthy lives and in addition provides mental health services to help remove barriers that prevent positive growth and development.	DSE

Department of Social Services (DSS)

Within DSS are three divisions that, in addition to other services, address the mental health needs of its clients. These three divisions are the MO HealthNet Division, the Children's Division, and the Division of Youth Services.

MO HealthNet Division (MHD)

In 2007 Missouri Medicaid was renamed MO HealthNet and the Division of Medical Services in DSS became the MO HealthNet Division (MHD). The purpose of the MHD is to purchase and monitor health care services for low income and vulnerable citizens of the State of Missouri. The agency assures quality health care through development of service delivery systems, standards setting and enforcement, and education of providers and participants. MO HealthNet processes claims for MO HealthNet recipients across the state of Missouri, including mental health claims for any mental health service received by any MO HealthNet recipient in the state. These claims primarily covered expenses for visits to physicians and mental health professionals for mental health concerns, pharmacy prescriptions, and in-patient mental health care services at non-state-funded hospitals or treatment centers.

Children's Division (CD)

CD provides treatment for all children and families in need of treatment services because of 1) abuse or neglect, or 2) at risk of abuse or neglect; and 3) children who have committed statute offenses such as repeated absences from school or who are in danger of becoming delinquent. Services include behavioral health services such as individual and group therapy, family therapy and other behavioral health interventions. The Office of Comprehensive Child Mental Health within DMH is working closely with the Children's Division to create a more coordinated system of care for children and families eligible for CD services. The Custody Diversion Protocol was developed in conjunction with DMH to prevent families from having to relinquish custody solely in order to obtain necessary mental health services for their child.


Division of Youth Services (DYS)

DYS is the state agency charged with the care and treatment of delinquent youth committed to its custody by one of the 45 Missouri juvenile courts. DYS is administratively organized into one central office and five regional offices. Services include assessment, care and treatment, and education of all youth committed to its care. Toward this end, DYS operates treatment programs ranging from non-residential day treatment centers through secure residential institutions. Additionally, DYS administers the Interstate Compact on Juveniles, operates an accredited school program, and maintains a statewide statistical database of juvenile court referrals. Youth offenders can be on probation or parole status or in the residential or diversion programs. All youth in residential programs are assessed using the Healthy Children and Youth screen that identifies existing and potential problems with health, including mental health. Planning for each individual youth is based on this assessment which presumes that unless health needs are mediated, youth cannot be successfully rehabilitated. The total number of youth served by DYS in 2006 was 2,793; 83% of whom were male. Of these youth, an estimated 63.5% had either serious or moderate incidents of

substance use, and 64.8% had either a diagnosed psychological/psychiatric disorder or behavioral indicators of a mental health disorder.

Department of Social Services Programs

Program or Service	Description
MO HealthNet and MO HealthNet Managed Care reimbursements	MO HealthNet processes claims for mental health, substance abuse, MR/DD costs for MO HealthNet (formerly Medicaid) and MO HealthNet Managed Care (formerly MC+ Managed Care) recipients.
Behavioral health care services for children and family who are victims of abuse and neglect.	The Children's Division (CD) provides treatment for all children and families in need of treatment services because of 1) abuse or neglect, or 2) at risk of abuse or neglect; and 3) children who have committed statute offenses such as repeated absences from school or who are in danger of becoming delinquent. Services include behavioral health services such as individual and group therapy, family therapy and other behavioral health interventions. (mental health services funded through DMH)
Custody diversion	The Custody Diversion Protocol was developed in conjunction with DMH to prevent families from having to relinquish custody solely in order to obtain necessary mental health services for their child (with DMH)
Juvenile Court diversion (mental health services through DMH)	<p>The Juvenile Court Diversion program is designed to divert juveniles from commitment to the Division of Youth Services through early intervention (family therapy, group counseling, etc.) and by working with less serious offenders at home. The programs are designed and implemented at the local level. Current programs funded include:</p> <p>(1) Drug Court Services Program, providing an array of services intent upon helping youth become clean, sober and successful in school, community and family.</p> <p>(2) Juvenile drug court, which treats juveniles committed for non-violent offenses and have substance abuse problems.</p> <p>(3) Residential treatment, targeted toward mentally disordered offenders within correctional facility. DMH provides on-site psychiatric care, psychiatric nursing care, licensed therapists, and targeted case management services. Services provided include individual and group therapy, substance abuse counseling and how to maintain non-violent lifestyle, especially for those associated with gang activity.</p> <p>(4) Advocacy/mentoring. Youth linked with adults who provide assistance and direction. Youth provided opportunities for skills-based learning in areas of team building, anger management, substance abuse through group classroom experience, and group recreation activities.</p> <p>(5) Drug abuse intervention program, which provides services to youth identified as "at risk" or whom have been identified as having alcohol or substance abuse problems. Initial drug screening to measure compliance; parent education on the effects of drugs and alcohol usage,</p> <p>(6) Parent Adolescent Conflict Education (PACE) – Parent Adolescent Communicating Together (PACT) & Mental Health/Substance Abuse Assessment And Treatment – (a) PACE offers services to youth and families referred to the court for assaults and other offenses. Program addresses responsibilities, life skills needed to manage anger, and education on</p>



conflict and anger; (b) PACT provides parents and youth with mediation services; and (c) RESPECT - is a restorative justice program holding youth accountable for their actions and making them part of the solution. Then Mental Health program contracts with social workers and treatment providers to address mental health and substance abuse issues of youth and in families.

Department of Health and Senior Services (DHSS)

DHSS is organized into three programmatic divisions: Community and Public Health, Regulation and Licensure, and Senior and Disability Services.

Division of Community and Public Health (DCPH)

DCPH administers programs addressing disease prevention and nutrition services, healthy families and youth, community protection, and provides public health practice and administrative support. DCPH currently provides a myriad of health prevention services to children and adults; some of which target similar issues as those targeted by ADA (tobacco use, fetal alcohol syndrome). Below are inventoried the DCPH programs which interface with mental health or substance abuse concerns, or the concerns of persons with developmental disabilities.

DCPH Programs and Services

Program or Service	Description
Alcohol, Tobacco and Other Drug (ATOD) Prevention and Awareness Program	Targets the prevention and/or reduction of the incidence of alcohol, tobacco, and other drugs in the preconception and prenatal periods. Provides substance use in pregnancy assessment and counseling forms to health care providers and ATOD educational brochures.
Injury and Violence Prevention	(1) Nine local Safe Kids coalitions in Missouri provide services to parents and children about the prevention of unintentional injuries among children under age 15. (2) ThinkFirst Missouri provided head and spinal cord injury prevention services to students in middle, junior high and senior high schools (3) Sexual assault awareness and to create community change needed to prevent sexual assault. (4) 25 agencies provide counseling, advocacy and support groups services for victims of sexual assault, including men, women, and children. (5) Forensic examinations for 263 adult and child victims of sexual assault. (6) Training module for local public health agency child care health consultants to train local child care providers about child passenger safety.
Building Blocks of Missouri	This nurse-family partnership operates in four sites: St. Louis, Kansas City, Springfield, and Cape Girardeau. It provides home visitation services for low-income, first-time mothers. Registered nurses begin services early in pregnancy and continue visitation through the child's second year. Nurses provide support, education and counseling on health, behavioral, self-sufficiency, and parenting issues. In FY07 4,799 visits were completed serving 455 families through the Building Blocks program.

Program or Service	Description
Comprehensive Tobacco Use Prevention Program	This program is dedicated to preventing tobacco use in youth, promoting quitting among youth and adults, eliminating exposure to secondhand smoke and reducing the impact on populations disproportionately affected by tobacco. To increase quitting among tobacco users, the Missouri Tobacco Quitline (1-800-QUIT-NOW) provides free cessation counseling services and referrals for local assistance. This program is coordinated with DMH's Division of Alcohol and Drug Abuse.
Special Health Care Needs	Individuals with special health care needs include those who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by individuals generally.
Hope Program	Hope Program provides assistance for children from birth to age 21 who meet financial and medical eligibility guidelines. Hope focuses on early identification of children with special needs; funds preventive, diagnostic, and treatment services; and provides service coordination for families. Service coordination is provided through 13 contracts and by Special Health Care Needs staff in regional offices in the state.
Council on Adolescent and School Health (CASH) –	The purpose of CASH is to inform and advise the DHSS decision-makers regarding adolescent and school health issues and initiatives. CASH has members representing the DMH's Divisions CPS and ADA
Missouri Fetal Alcohol Syndrome Rural Awareness and Prevention Project (MOFASRAPP)	MOFASRAPP is a Fetal Alcohol Syndrome Project Collaborative project involving DHSS, DMH, Missouri Institute of Mental Health(MIMH), University of Missouri-Columbia, and St. Louis ARC. The project covers 71 rural counties. Activities include: (1) Reducing alcohol-exposed pregnancies in at-risk women ages 18-44; (2) Educating health care providers on Fetal Alcohol Syndrome (FAS), alcohol exposure and reproductive risk factors for women of childbearing age (12-44); (3) Establishing a FAS Center to provide diagnostic, referral and follow-up services for persons suspected of having an alcohol related condition and their families; and (4) Enhancing existing surveillance systems to monitor the prevalence of alcohol consumption and contraceptive practices in women of childbearing age, and the incidence of AFAS.
Missouri Fetal Alcohol Syndrome Action and Care Team (MOFASACT)	The mission of MOFASACT is to raise public and professional awareness of Fetal Alcohol Syndrome, one of the leading preventable causes of mental retardation, through prevention, education and advocacy.
Missouri Community-based Home Visiting Program	This funds an interdisciplinary team intervention to support women and their families through the post-partum period or through the growth of a child to age three. This is a home visiting model.
Suicide Prevention Plan and Suicide Prevention Advisory Council	While DMH is the lead agency on this initiative, DHSS partnered with DMH to design a Missouri Suicide Prevention Plan and sits on the Suicide Prevention Council which helps to coordinate and guide prevention activities. DHSS is also the repository of data on suicide and suicide attempts in Missouri through DHSS' Missouri Information for Community Assessment (MICA) data tables.

Division of Regulation and Licensure (DRL)

DRL regulates and licenses child care facilities, hospitals and ambulatory surgical centers, home health and hospice providers, long-term care facilities including assisted living, residential care, intermediate care, and skilled nursing facilities, emergency medical services, pharmacies and persons authorized to prescribe or dispense controlled substances. Some residential care facilities are co-licensed by both the DRL and the DMH. Many consumers reside in DRL licensed facilities.

Division of Senior and Disability Services (DSDS)

DSDS serves as the State Unit on Aging, and carries out the mandates of the State of Missouri regarding programs and services for seniors and adults with disabilities. DSDS investigates allegations of elder abuse and administers programs designed to maximize the independence of seniors and persons with disabilities who are at risk of unnecessary or premature institutionalization.

DSDS Programs and Services

Program or Service	Description
Adult Protective Services	<p>DSDS maintains an Elder Abuse and Neglect Hotline (1-800-392-0210) which operates 24-hours a day, 365-days a year. It responds to reports of alleged abuse, neglect or financial exploitation of persons 60 years of age or older and other eligible adults between age 18 and 59. The program provides investigation, intervention and follow-up services to victims and stresses the mentally competent adult's right to make their own decisions. Persons with developmental disabilities and/or mental illness who cannot protect their own interests are among the eligible adults.</p> <p>Reports of abuse, neglect or other complaints regarding Long Term Care Facilities are also registered at the Elder Abuse and Neglect Hotline. Investigations are completed by Long Term Care survey staff around the state.</p>
Area Agencies on Aging	<p>The Area Agencies on Aging (AAAs) are not part of DSDS, but, as the State Unit on Aging, DSDS has the responsibility of coordinating and overseeing the AAA state plans. One of the assurances which the State must see is met by each AAA reads as follows: Each area agency will, in coordination with the State agency and with the State agency responsible for mental health services, increase public awareness of mental health disorders, remove barriers to diagnosis and treatment, and coordinate mental health services (including mental health screenings) provided with funds expended by the area agency on aging with mental health services provided by community health centers and by other public agencies and nonprofit private organizations.</p>

Program or Service	Description
Home and Community Services	<p>Many seniors and disabled younger adults can remain in their own homes and avoid or delay institutionalization with the help of support services. The Division of Senior and Disability Services administers a coordinated, integrated home and community service delivery system to assure that the needs of Missouri's elderly and persons with disabilities are met.</p> <p>Through statewide staff, services such as personal care, homemaker, chore, nursing, respite, adult day health care, counseling, and consumer-directed services are made available to the elderly and persons with disabilities in their homes.</p> <p>These supportive services are provided to eligible persons 60 years of age or older and to adults with disabilities between the ages of 18 and 59. Generally, the service recipient must meet specific guidelines concerning economic, social, and care needs in order to be eligible for home and community based services. Through an assessment process, the division determines the services necessary to meet the needs of each eligible person. The primary funding sources for home and community based services are General Revenue, MOHealthNet, Social Services Block Grant, and the Older Americans Act. Through these programs, approximately 66,000 elderly and persons with disabilities receive supportive services each year.</p>
Case Management	<p>Case management provides ongoing assessment and service coordination provided by DSDS staff for elderly and disabled persons receiving in-home and/or adult protective services. Persons with developmental disabilities and/or mental illness are eligible for and receive case management services.</p>

Department of Corrections (DOC)

DOC provides a wide array of mental health and substance abuse services to inmates its prison population, referring its offenders with mental illness issues to the sexual offender treatment at Farmington; level 4 and 5 treatment at Fulton; MR/DD housing and treatment at Potosi and substance abuse treatment at several DMH facilities. All inmates receive mental health and substance abuse screening and assessment upon entry into the correctional facilities. Treatment beds are spread throughout the state from minimum- to maximum-security institutions. A total of 242 beds are available for those with mental illness, 850 beds for substance abuse treatment, and 46 beds for MR/DD clients. In 2006, 4473 offenders were classified at levels 3-5 in 2006 which entitled them to services. This represents 38.4% of the prison population.

Fewer services are available to transition inmates with mental illness into the community. Currently, DOC is collaborating with DMH on an initiative wherein the DMH Community Mental Health Centers (CMHCs) provide services to mentally ill persons recently released from correctional facilities. Out-patient services provided through the DOC for mental health issues are also available to those with substance abuse issues including the Post-conviction Drug Programs and the Cocaine Addiction Program. Both triage approaches

to serving those with mental illness as well as diversion programs are expressed needs for these individuals.

Department of Corrections Services and Programs

Program or Service	Description
Inmate screening and assessment for mental illness and substance abuse	All inmates receive screening and assessment upon entry into correctional facility
Mental health treatment services (inmates)	DOC contracts with a private company to provide mental health treatment services to inmates. Private contractor has staff of over 150 providing services in all 21 correctional facilities.
In-mate substance abuse treatment services	<p>(1) The Cocaine Addiction Program lasts up to 18 months for offenders who are in need of long-term drug treatment for long-term addictions.</p> <p>(2) Offenders Under Treatment is a 180-day treatment program for those whose drug problem was a precipitating factor in their offense.</p> <p>(3) The Post Conviction Drug Treatment Program is designed for probationers who have failed to complete treatment within the community.</p> <p>(4) 12-step programs (in prison and in the community) and other support and education programs</p>
Alternative to traditional incarceration for substance abusers	Department Institutional Treatment Centers (ITCs) provide substance abuse treatment for inmates, parole, and probation violators at eight correctional centers.
Drug screening	Routine drug screening for all inmates and offenders. Screenings assist corrections professionals in assessing, evaluating and referring inmates and offenders to appropriate substance abuse programs within the institutions and the community.
Probationer substance abuse treatment services	Required Assessment, Education and Treatment (REACT) is a statewide program for persons placed on probation by the Court for a felony drug offense. Offenders must submit to an assessment within 60 days of their term of probation as a condition of probation and then address the causes identified in that assessment through substance abuse education and treatment programs. REACT also increases offender accountability by requiring probationers to pay for all or a significant portion of the program services, depending on financial ability (with ADA).

Department of Public Safety (DPS)

DPS Juvenile Services Division has the goal of creating opportunities for youth to prevent them from engaging in violent activities. The Division receives funding through the U.S. Office of Juvenile Justice Prevention to fund programs including those that focus upon risk and protective factors. The Division also has a block grant program that funds programs on school safety, juvenile drug courts, training for law enforcement and court personnel to control crime. Programs also exist to enforce Underage Drinking Laws within the Division of Tobacco and Alcohol Control. The Drug Awareness and Resistance Education (D.A.R.E) program offered throughout the state is funded through the DPS. Details regarding each of the implemented programs will follow in Year Two.

Office of State Courts Administrator (OSCA)

OSCA operates five mental health courts (in St. Louis City, Jackson County, St. Louis County, Greene County and Boone County). While offering no mental health services, they also route youth in the juvenile justice system to the DMH to receive treatment for mental health issues.

Cross-departmental Initiatives

Mental health care at the state level is offered primary through the DMH, but six other departments either directly offer or contract with DMH for substance use, mental health and/or MR/DD services, resulting in a fragmented system of care. Advisory boards and commissions often involved multiple departments. Some initiatives are coordinated across departments, and grants have required the creation of state advisory boards for the duration of the grant period. Examples of current collaborative efforts are listed below.

Initiative	Description	Departments/ Divisions
Office of Comprehensive Child Mental Health	The Office of Comprehensive Child Mental Health (OCCMH), in partnership with other child serving entities, has helped develop local community-based services for children with serious mental health needs and their families (Systems of Care). Available in seven counties and the City of St. Louis. OCCMH is working closely with DMH and DSS's Children's Division to create a more coordinated system of care for children and families eligible for CD services. State efforts through the legislatively mandated Comprehensive System Management Team (CSMT) have helped to establish an integrated, inter-agency, community-based system of care in 11 Missouri counties and the City of St. Louis.	DMH, DSS, DHSS, DESE, DOC, DPS, OSCA
Suicide Prevention Advisory Committee	The Suicide Prevention Advisory Committee is directed to advise on and promote suicide prevention and review related policy and promote the use of evidence-based practices. The Committee is charged with producing a bi-annual report on the status of suicide prevention in Missouri, establishing annual goals and objectives for suicide prevention in Missouri, reviewing programming to prevent suicide across the state, and identifying areas for policy change including legislation.	DMH, DHSS, DSS, DESE, DOC, Department of Higher Education, Missouri House of Representatives and Missouri Senate
Child Abuse Prevention	DSS has convened a cross-departmental, public/private agency collaborative to develop a Child Abuse Prevention Plan for the state. Called Missouri Prevention Partners, the group conducted an inventory of child abuse prevention programs, reviewed initiatives from other states and is developing goals and objectives for Missouri's Plan.	DSS, DMH and other departments
Strategic Prevention Framework State Incentive Grant (SPF-SIG)Advisory Committee	The SPF-SIG, operated out of DMH's ADA, requires an advisory committee to oversee the grant efforts. Committee members include representatives across seven departments involved in prevention efforts.	DMH, DHSS, DSS, DESE, DOC, OSCA

Initiative	Description	Departments/ Divisions
Pre-release planning	DOC and DMH collaborative to work with DMH Community Mental Health Centers to plan mental health programming for prisoners transitioning into the community CMHCs will be providing services to mentally ill persons recently released from correctional facilities. Service activities include (1) reviewing inmate history, (2) providing clinical information to CMHC providers who will serve the transitioning inmate upon release, (3) participation in the development of transition plans, and (4) scheduling immediate services for the offender to receive from CMHC staff following release.	DOC/DMH
The Offender Reentry Program	The Offender Reentry Program, led by the DOC, is an interagency team addressing offender reentry.	DOC, DSS, OSCA, DMH, DOR, DHSS, DED, DESE
Process Success	Project Success is a demonstration project to expand employment opportunities for individuals with mental and/or physical disabilities who receive public support.	DESE: DVR and Division of Adult and Vocational Education; DSS, DMH, DED.
Bright Futures	Bright Futures targets current and emerging preventive and health promotion needs of infants, children and adolescents who have mental and emotional disorders. Also targeted are other issues such as developmental problems, educational failure, too much risk taking, lack of supervision, and child abuse.	DHSS, DESE
Missouri Fetal Alcohol Syndrome Rural Awareness and Prevention Project (MOFASRAPP)	MOFASRAPP involving DHSS, DMH, MIMH, University of Missouri-Columbia, and St. Louis ARC. The project covers 71 rural counties and addresses alcohol-exposed pregnancies, health care provider education, establishing a FAS Center to provide diagnostic referral and follow-up service, and enhance existing surveillance systems to monitor the prevalence of alcohol consumption and contraceptive practices in women of childbearing age.	DHSS, DMH, MIMH University of Missouri-Columbia, St. Louis ARC

Initiative	Description	Departments/ Divisions
Other Initiatives	Other cross-departmental services/initiatives not listed above include:	
	(2) Missouri Alliance for Youth,	DMH and DSS
	(3) the Missouri Student Survey,	DMH and DESE
	(4) The School-based Services Committee.	Chaired by DSS, includes several state agencies
	(5) A proposal to expand school-based mental health services is currently under review.	DESE and DMH
	(6) Medicaid Pharmacy Project	DMH and DSS
	(7) Medical Risk Management	DMH and DSS

Other Mental Health Services and Funding

In addition to mental health services provided through the state departments and described above, there are also mental health resources that are available through the Federally Qualified Health Centers (FQHCs), not-for-profit agencies (United Way, etc.), private foundations and local hospitals. Furthermore, for those individuals with the ability to pay for services or those with health insurance with mental health care coverage, the network of providers expands to include all professionals and/or facilities providing mental health care services to individuals in Missouri. Services are available through local mental health care agencies, hospitals and clinics, psychiatrists, private psychologists, licensed clinical social workers, licensed marriage and family counseling therapists, and other mental health professionals. Funding is provided from an equally varied assortment of sources, including mil taxes (11 counties).

The second year NARI will include a more complete inventory of other mental health services, resources, and funding that is available in Missouri.

Statewide Consumer-operated Services

Consumer-directed Service Programs (COSPs) in Missouri

During the first year of the Transformation grant, the environmental scan of consumer involvement in the mental health system was limited to consumer and family support services and a cursory look at consumer/family member organizations. The planned census of consumer and family involvement in the mental health service delivery system in year two will provide a comprehensive overview of peer resources, supports, and service gaps by geographic and demographic characteristics of the consumer population. However, some patterns have emerged from this preliminary survey.

There are a number of organizations that are either consumer-run or which have consumers as providers. Some of these have advocacy as their primary mission; some are primarily geared toward service, education and/or support; and others are affiliated with governmental agencies. As relates to traditional consumer/family member organizations, most have local geographic membership. There are, however, several organizations with regional or state-wide membership for persons with mental illness, substance abuse problems and MR/DD. In the mental health area, consumer-run organizations include but are not limited to COSPs, drop-in centers and warm lines.

Consumer-operated Organizations

Organization	Description
National Alliance on Mental Illness (NAMI)	NAMI is the nation's largest grassroots mental health organization dedicated to improving the lives of persons living with serious mental illness and their families. NAMI of MO has 13 affiliates in Missouri with over 909 members. NAMI is involved in legislation, fund raising, facilitator training, warm line provision, Family-to-Family, Peer-to-Peer, In Our Own Voices, and NAMI Connections (NAMI Care) program. NAMI Connections trains peer facilitators to conduct support groups and runs support groups for consumers.
Consumer-Operated Service Programs (COSPs)	COSPs are peer-run service programs that are owned, administratively controlled, and/or operated by mental health consumers. They emphasize self-help as their operational approach. COSPs may be called by other names, such as consumer-run organizations, peer support programs, peer services, or peer service agencies. The services offered by COSPs often include: peer counseling and peer-to-peer support; assistance with basic needs or benefits; help with housing, employment or education; linkage to services or resources; social and recreational opportunities; arts and creative expression; formal support groups and structured educational groups and training.

Organization	Description
Missouri Recovery Network (MRN).	The MRN membership includes persons who are in personal recovery from substance abuse, their family and friends. There is a state-wide council of 17 members with representation across the five ADA regions (NW, C, S, SE, and SW) with half of those on the council in personal recovery. There are currently 1,138 members statewide. MRN is also working with Committed Caring Faith Communities in St. Louis to educate the clergy and others about substance abuse.
MPACT (Missouri Parents Act).	MPACT is a statewide, non-profit, independent parent center, serving parents of children with all disabilities. MPACT was started by parents of children with disabilities and is staffed primarily by parents. Serves approximately 10,000 people a year and employs staff in various parts of Missouri.
Self Advocates and Families for Excellence (SAFE).	SAFE is a statewide volunteer organization consisting of people with developmental disabilities, self advocates, and family members of people with developmental disabilities. Trained SAFE volunteers work in conjunction with the DMH's MR/DD to help gather information directly from individuals with developmental disabilities about the services and supports they receive; how individuals with developmental disabilities feel about their lives; and to help determine the presence of the Missouri Quality Outcomes in their lives.
Arc of the United States, Missouri Chapter.	The ARC of the U.S., Missouri Chapter, is an organization of parents of children with disabilities, family members, self-advocates and disability professionals working together to support and empower individuals with developmental disabilities and their families through advocacy and education. It aims to expand individual choices and promote community inclusion.
Retardation Association of Missouri (RAM).	RAM is an organization of parents and friends working on behalf of persons in Missouri with mental retardation. The organization promotes issues on behalf of persons who reside in Missouri's state-run habilitation centers including lobbying for more funding on behalf of the residents, for pay increases for direct care staff, and ensuring that staffs who have abused persons in state facilities are terminated.
The Family Bridges (regional)	The Family Bridges serves families whose children have severe emotional disorders and co-occurring diagnosis. The organization is 2 years old and was incorporated in January 2007. A paid membership available in the following Missouri counties: Greene, Christian, Taney, Stone, Barry, and Lawrence and plan to expand throughout the southwest region of Missouri. In January 2007 there were 200 participants including children/youth and adults.
SCOPE (Supporting Consumer Operated Program Enhancements)	SCOPE is a statewide consumer provider network composed of staff and members of the drop-in centers, whose mission is mutual support and empowerment among peer programs through shared skills and learning, leadership building, and community collaboration.

Organization	Description
Procovery™	The Procovery™ program, developed by Kathleen Crowley, author and Executive Director of the Procovery Institute, emphasizes a hope-centered, forward-focused, and skills-based partnership of the consumer, the family, the service provider, and the community. It includes eight principles for resilience in healing, twelve strategies for action, and a highly structured system, known as the Procovery Circle, for group training and support.
BRIDGES (Building Recovery of Individual Dreams and Goals Through Education and Support).	BRIDGES is a peer-to-peer education and support group program for adults. The program has two components. It provides a 10-week education course followed by a support group with trained teachers and facilitators. The program is modeled after the “Journey of Hope” family-to-family education course.

Technological Resources

The technology working group assembled as part of the transformation planning stage identified 46 data sources that serve to inform the state regarding its mental health care system. Below is a table listing all of the current technology resources.

Current Inventory of Technological Resources

#	System Name	Owner	What it Tracks	Purpose/Scope*
1	CIMOR	DMH	Consumer demographics, Providers, Services, Billing and payment, Assessments, Admissions, Program assignments	Track all information needed for consumers, services provided, and payment for services. Includes Substance Abuse Treatment program and interface with DOR for driver licenses.
2	MO Telehealth	University of Missouri	No stored data	Service Delivery - Telemedicine including tele-psychiatry. (Some locations across the State.)
3	CIMOR EMT	DMH	Abuse / neglect, grievances, incidents	Event Management and Tracking for all consumer-related risk incidents, investigation, and follow-up. Adding staff misconduct functionality.
4	ACTS – Alternative Care Tracking System Being replaced by FACES see # 43	DSS	Demographic data; placement information; federal funding eligibility	Tracks information regarding child's placement; Medicaid, IV-E, EAS, and Rehab federal funding; legal status, court information, handicapping conditions, etc.
5	CSIPS – Children's Services Integrated Payment System - Being replaced by FACES	DSS	Child-specific payments	Tracks vendor and child specific payment information by payment date, funding source, and service.
6	SEAS - Being Replaced by FACES see # 43	DSS	Service Authorization System	Tracks authorization by child/family and vendor by service.
7	REJIS (Regional Justice Information System)	City & County of St. L.	Access to State and National criminal records.	REJIS provides access to the state and national criminal databases maintained by the MSHP (MULES system) and the FBI (NCIC) system. Access is limited, within DMH, to specific individuals working in Forensic Services.
8	CHRIS – Client Habilitation Records Information System	Boone County Family Resources	Consumer demographics; plan of care authoring and management; service authorization; providers; admission and discharge; billing and payment	Track consumer information, manage plans of care, procure services, and documentation of expenditures. Used by some SB-40 Boards for TCM billing. (Some locations across the State)

#	System Name	Owner	What it Tracks	Purpose/Scope*
9	Missouri Rehabilitation Information System	DESE	VR Case Management	Comprehensive case management system including VR case work flow from intake to closure. Integrated with the SAMII accounting to provide an efficient method for making all case service payments using paper checks or direct deposit. Provides financial and statistical reports and case management reports.
10	OPII	DOC	Offender information – institution; probation & parole	Tracks information needed to manage offenders that are being supervised by the department of corrections.
11	MARS (Medical Assessment and Reporting System)	DOC	Mental Health; substance abuse; medical	Tracks health information for offenders under the supervision of the department of corrections.
12	DMS-MMIS, EMOMED, Cyber Access	DSS	Medicaid payments, services, eligibility	This system authorizes Missouri Medicaid payments for eligible clients and services.
13	Child & Adolescent Functional Assessment System (CAFAS)	DMH	Basic Child demographics, assessment results.	Assessment for children, support for treatment/service planning and outcomes over time. (A few locations across the State - plan to go to all DMH locations and others)
14	QSR – Quality Services Review	DMH / Children's Division	Not sure	Quality Service Review (QSR) developed by Dr. Ivor Groves is used to measure system of care quality improvement. It measures the quality of interactions between frontline practitioners and children and their families and the effectiveness of the services and supports provided. It is a case based review of practice, results, and working conditions used to both evaluate and stimulate practice development
15	Network of Care	DMH - outsourced to Trilogy vendor	Informational site for family and stakeholders. Little or no transactional data.	Website for service access, research, etc.
16	Community Connections	University of Missouri	Community Providers; Human Services	Resource for various human services and organizations searchable by area and specialties. May be closing down.
17	SAMHI	MIMH	Contact information for mental health, substance abuse, and mental retardation service organization	Substance Abuse Mental Health Information (SAMHI) Online is a publicly funded site designed to help consumers, families, and professionals locate services and information relating to mental health, addiction, and mental retardation services in the St. Louis, Missouri area. http://samhi.mimh.edu

#	System Name	Owner	What it Tracks	Purpose/Scope*
18	MOHSAIC	DHSS	Health/Scorecard info for Senior Services; VR; NB Screening; Immunization; Communicable Disease. Program enrollment, participation demographics, progress notes, services authorized, provider information, and claims management	This is a web-based data system that collects information for newborn screening, lead and immunization. There are other databases within DHSS that collect immunization information and communicable diseases that are fed into MOHSAIC. MOHSAIC Service Coordination is the electronic record for Special Health Care Needs Programs.
19	MOJJIS	OSCA	Contacts and some information about juveniles served by various agencies	Allows sharing of information across agencies for coordinated services and decisions regarding children
20	IDEA (Individuals with Disabilities Education Improvement Act)	DESE	Guidelines and standards	Sets standards for improved education for individuals with disabilities.
21	DWITS	MSHP	Drinking; DWI	The DWI Tracking System (DWITS) is a secure Internet - based computer application that improves the collection and dissemination of case information on alcohol / drug - involved driving and traffic related offenses. It can be used to track driving while intoxicated (DWI) cases through their entire life cycle including arrest, prosecutorial action, and court disposition.
22	FAMIS	DSS	Provider Registration, Child Care, Food Stamps, Temporary Assistance for Needy Families, and Family Medicaid	FAMIS is a statewide, automated, integrated eligibility system for DSS programs including Child Care, Food Stamps, Temporary Assistance and Medicaid.
23	MACCS	DSS	Child Support Enforcement	MACCS processes and tracks the child support payments made to all persons in the State of Missouri, as well as some in other states and countries.
24	MMIS – Medicaid	DSS	Medicaid claims processing system.	Pays vendors for medical services provided to clients based on eligibility.
25	Common Client/DCN	DSS	Maintains basic non-changing demographic information i.e. race, sex, DOB, Name, etc. Also, Department Client Number (DCN) is a unique identification number used by DSS, DHSS and others to track participation in programs.	Client identification and participation tracking.

#	System Name	Owner	What it Tracks	Purpose/Scope*
26	LTACS – Long-Term Alternative Care Systems	DHSS	Tracks client data	Includes level of care, types of services, funding sources, protective services information and Title XIX eligibility for persons in Long Term Care.
27	Family Care Safety Registry	DHSS	Persons who have been disqualified from providing care	Provides background information on potential caregivers. Families and employers can call the registry's toll-free telephone line to request background information on registered child-care, elder care, and personal caregiver workers or to request licensure status information on licensed child-care and elder care providers.
28	Missouri Sex Offender Registry	MSHP	People convicted of Sexual Offense	Provides public access to information about persons registered as sexual offenders. Individuals included on the site are included solely by virtue of their conviction record and Missouri state law. The primary purpose of providing this information is to make the information easily available and accessible, not to warn about any specific individual.
29	Traumatic Brain Injury Registry	DHSS	Hospitals submitted registry on incidents of traumatic brain injury, demographics of injured person, and cause of injury.	The registry data provides information on incident rates, location of injuries, and causes. Customized reports of registry information can be obtained from the DHSS website.
30	EMSystem	MHA	ER Availability; Psychiatric Bed Availability	Missouri Hospital Association's (MHA) statewide, Internet-based communications system linking hospitals, major metropolitan emergency services providers, local public health agencies and the DHSS. Used daily to help hospitals update, monitor, and report ambulance diversions. Real-time communications of public health alerts and clinical treatment information between public health agencies and hospitals.
31	No Interface Exists - all services are tracked through FACES	DYS		
32	DSS Vendor System - Being replaced by FACES see # 43	DSS	Vendors utilized by CD clients	Tracks vendor licensure and contract information, including address, capacity, services, etc.
33	Child Abuse/Neglect System - Replaced by FACES see # 43	DSS	All reports of abuse/neglect	Tracks allegations, alleged victims, alleged perpetrators, disposition of investigation or assessment

#	System Name	Owner	What it Tracks	Purpose/Scope*
34	EARN Works	Office of Disability Emp. Policy (federal)	National Job Bank for Employment	Provides information on employment opportunities
35	Ticket To Work - MAXIMUS	SSA	Provides Reports, Sends list of participants who just were determined to be disabled	Encourages individuals to earn a living wage. Resource to organizations providing employment services to target individuals who need employment services.
36	One Stop Tool Kit	DOL (federal)	List of resources for organizations to use for training and also training materials	Resources for organizations delivering Employment services
37	RCEP 7	University of Missouri	Provides information on training opportunities and entitlements	Resources for organizations delivering Employment services. This is a Rehabilitation Continuing Education Program in 4 states (MO, KS, NE, IA)
38	REAC-Real Estate Assessment Center	HUD	Information assessing the condition of HUD's portfolio	Provides information to help ensure safe, decent and affordable housing. Verification of information for recertification process; Verification of payment and non-payment and reason.
39	WIA (Workforce Investment Act)	DED	unemployment	Offers career development, skill development, employer job posting, job search and job matching, all in an environment that is known as Missouri Career Centers. Centers are located throughout the state; they have about 41 Missouri Career Centers. Virtual (Internet) access to the system is provided by a web-site called GreatHires.
40	Access Crisis Intervention (ACI)	DMH Providers	No stored data	DMH contracts with providers to staff phone lines 24/7 with mental health professionals who can respond to a personal crisis. They help determine what further help is needed immediately or later.
41	2-1-1 System	United Way	Social services contacts	Phone Information and Referral system for health and human services Now largely statewide in Missouri.

#	System Name	Owner	What it Tracks	Purpose/Scope*
42	Family and Children Electronic System (FACES)	DSS	Demographic data; placement information; federal funding eligibility, child-specific payments, service authorizations, vendors and all reports of abuse and neglect	Tracks information regarding child's placement; Medicaid, IV-E, EAS, and Rehab federal funding; legal status, court information, handicapping conditions, vendor and child specific payment information by payment date, funding source, and service. Tracks vendor licensure and contract information, including address, capacity, services, allegations, alleged victims, alleged perpetrators, disposition of investigation or assessment
43	Fetal Alcohol Syndrome Surveillance System	DHSS		
44	IAN (Interactive Autism Network)	Kennedy Kieger Foundation	A variety of self reported demographics, medical, social and treatment history on persons with ASD history.	A voluntary online national registry designed to accelerate the pace of autism research and treatment.
45	ScreenMO	MIMH	Anonymous screening information	ScreenMO offers free self-assessments to help adolescents (or concerned others) decide if they have difficulties for which professional assistance is available. Individuals can take a brief (less than one minute) screen to help identify problems and get referral information. Areas assessed include Employment, Legal problems, Substance use, Depression, MR/DD, Housing, Tobacco use, Medical, Bipolar. Based on the screening information the system offers referral suggestions (in the St. Louis area) and includes specific authoritative information links. www.ScreenMO.org

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